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**Lessons for inclusive citizenship?
Difference, disability and rights in the lives of
people with learning disabilities who have
high support needs**

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**Submitted in fulfilment of the requirements for the Degree of
Doctor of Philosophy**

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Abstract

Policy in Scotland, as in the rest of the U.K, aims to enable people with learning disabilities to access the same opportunities as other citizens. This thesis explores the meanings and experiences of citizenship and inclusion in the lives of people who challenge services the most, whether because of profound impairment, vulnerability or perceived risk to others. Case studies were conducted with 14 individuals with learning disabilities who were assessed as needing at least one-to-one support in their day centre or supported living setting, or who were considered difficult to discharge from long-stay hospital. Through interviews and observations I sought to identify the barriers to and safeguards of inclusion in their daily lives. Perspectives on the issues affecting service provision were obtained through telephone interviews with commissioners in 28 out of 32 local authorities in Scotland, conducted at the time of 'The same as you?' review. I argue that the notion of the rights-bearing citizen should be extended to embrace vulnerability, differences in capacity and the need for advocacy in order to develop practices that do not systematically marginalise some people within a new normalcy of active citizenship. I also reflect on my own learning about the conduct of inclusive research from working with study participants with high support needs.

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Preface

Entering our office building one day, I saw a taxi driver bumping a passenger in a wheelchair to the ground, instead of using a ramp. On looking closer I saw that the person was one of my research participants whom I had not seen for several years. The following week I saw him and his two support workers in the canteen. They had been to the next door swimming pool. On the face of it, little about his life had changed. Remembering how powerfully I had been affected by meeting him, I was struck by the difference between the impact he could have on others and the apparently gigantic obstacles to bringing about even small changes in his own circumstances. Maybe it was worth trying to finish that thesis after all ...

This thesis is about the conditions for inclusive citizenship as exemplified in the lives of people with learning disabilities who challenge services and society the most. It considers the ways (Joint Committee on Human Rights, 2008) in which both assumptions of incapacity, and failures to recognise the social value of relationship and participation, create inequalities and disable people who require support to engage with others. I argue that recognition of incapacity as a universal identity would provide a basis for a more just social contract, improve society's capacity for inclusive communication, and challenge the discrimination of people disabled by mainstream assumptions of active citizenship, legal capacity and social responsibility.

In the past, people with learning disabilities have experienced exclusion and the abrogation of their rights through policies of segregation, inadequate support, and low expectations of their capacities (O'Brien and Lyle, 1987). Despite much greater recognition of their rights to opportunities on the same basis as other citizens, exemplified in policies across the U.K., there is evidence of continuing discrimination in their access to justice and to their social rights through education, healthcare, housing and employment (Joint Committee on Human Rights, 2008). People with learning disabilities face additional barriers through negative representation, harassment, and failures to support their human rights to live their lives with dignity, equality, respect and autonomy, as exemplified

by the struggles of people with learning disabilities to receive support to parent (Tarleton and Ward, 2007).

There has also been real progress in the aspirations, services and opportunities available to many people with learning disabilities, through developments over several decades. However there is agreement that these benefits have not been equally shared. People with the most severe impairments have generally benefited less from changes in service development, and are currently considered also to have been left behind by the policy initiatives of the last decade (Felce, 1998). Particularly disadvantaged are people with profound impairments and complex health needs and people with behaviours that challenge services or additional mental health needs (Department of Health, 2007, Mansell, 2009).

Whilst the barriers experienced by people with learning disabilities have increasingly been theorised within the social model of disability, research interest in those with more severe impairments and additional needs has on the whole been stronger in psychology than in sociology, with the exception of studies of people in long-stay institutions (Johnson and Traustadodottir, 2005, Johnson, 1998). Moreover, there is an irony that current social policies, with their emphasis on equality of opportunities, active citizenship and labour force participation, which have been embraced as mechanisms to achieve better lives for people with learning disabilities, may increase the marginalisation of people who will not compete on equal terms as economic actors (Williams, 2005).

My research builds on the tradition of inclusive research with people with learning disabilities (Walmsley and Johnson, 2003) to explore how people who are often not included as mainstream research participants because of profound impairment, communication difficulties or other additional needs could contribute their experiences to an understanding of the meaning of social inclusion. I give an account of my learning in adapting qualitative approaches in these circumstances and I conclude that, given flexibility and an attentive stance, researchers can develop their competence to hear the experiences of people whose communication and understanding of the world may be only partially accessible to them.

The study began from a concern with social justice. Why were some citizens experiencing segregation and not being considered eligible for the opportunities available to others? A visit to a long-stay hospital for people with learning disabilities made me aware that there were lives being lived outside the scope of services that I had previously studied and people whom I never encountered as neighbours or colleagues. That experience was the starting-point for this study.

My aim was to understand how services could become more inclusive by focusing on the experiences of people who were pushing the capacity of the service system to its limit. I therefore chose to use a measure of the level of support required as the entry criterion for the study. Since support hours account for the largest element of expenditure in social care, I focused on the experiences of people assessed as requiring at least one-to-one support on a 24 hour basis.

The Three Research Questions:

What were the daily experiences of inclusion of people with learning disabilities and high support needs, and what did home and belonging mean for them?

How feasible would it be to include people with these support needs in research to address this question, and what could be learned from this experience?

How did the ways in which services were developed and provided structure both the available opportunities for inclusion and contribute to the experiences that people had?

There were two empirical elements to the study. I conducted case studies with 14 people who were receiving one-to-one support or were considered very difficult to discharge from long-stay hospital. I used qualitative methods to explore their experiences and adopted an ethnographic approach to gathering information from them, their families and their support staff. In order to examine the influences on service development, I conducted a survey of lead commissioners from local authorities across Scotland. I used telephone interviewing to obtain their opinions on inclusion and whether they saw community living as an option for everyone. 28 out of 32 local authorities in

Scotland were covered by the survey. By bringing together these two different sets of data, I show how people whose needs challenged services often occupied a marginal status and experienced support that did not promote their autonomy and inclusion. However, through the research, they revealed themselves as desirous and capable of agency and participation.

The Thesis Structure:

In Chapter One I situate ‘The same as you?’ Review of learning disability services in Scotland in the history of Learning Disability practice, and in particular ‘ordinary life’ principles, together with the policy framework of late 1990s and beyond, in which access to opportunity was embraced as a mechanism to tackle inequalities. I argue that both these frameworks have limitations in addressing the discrimination that people with learning disabilities experience in accessing their social rights. I then consider these issues as an aspect of the tension between difference and equality in citizenship (Lister, 2007b) and disability (Shakespeare, 2006) theory, in order to highlight the ways in which the exclusion of people with learning disabilities is inscribed in the Western tradition of independent decision-making and legal capacity.

Chapter Two continues my review of literature and provides the background to the Methods Chapter that follows. In it I discuss the development of research with people with learning disabilities and in particular the influence of the social model of disability upon both research in general and on the thinking and practice of emancipatory and inclusive research in particular. I then ask who has been left out of inclusive research, and I look at some of the barriers to research involvement by people deemed to lack capacity.

In Chapter Three I set out my research aims, describe my methodological approach and my research design. I explain how I recruited participants for the study, the methods I used, and how I dealt with the ethical issues that I encountered. I came to see my research as an interaction and the data as co-produced with the study participants. I conclude with a reflexive account of my research.

Chapters Four to Six contain my analysis of the data from the case studies. Chapter Four, 'Moving Beyond Categories: relationship, resistance and recognition', explains how the study participants enabled me to find out about them, reflects on their agency and capacity to resist power, and describes what I learnt about communication in research encounters. Chapter Five, 'Interpreting Needs and Claiming Resources', explores the reasons that people were deemed to require a high level of support, as an example of the way that 'needs' are constituted by service systems. It also explores two examples of the struggle for recognition of needs and, following Fraser, I view these as 'needs claims' that reveal where public responsibility for certain needs was being contested. Finally, I describe the results of these contests for the study participants, with health and communication needs being particularly unlikely to receive support. Chapter Six, 'Being and Becoming at Home and in the Community', then examines how inclusion and exclusion was experienced in the lives of study participants. I explore both what home and community seemed to mean to them and their experiences of belonging or exclusion. I conclude that relationship was fundamental to their capacity to be themselves, feel secure, and develop wider networks.

Chapter Seven, 'Strategic Planning for Inclusion', reports on the survey of those responsible for planning services in Scotland at the time of 'The same as you?' Review. In the light of the experiences of the case studies, it asks why funding and services might not be made available to meet identified need. It describes how the idea of inclusion was contested, with some commissioners viewing community living as a goal they should strive to achieve for everyone, while others thought that services in the community could only be available up to a certain limit of needs and costs. Variations in infrastructure and problems in modernising services accounted for some of the difficulties in responding to needs, but a significant issue was the lack of shared responsibility between health and social work agencies for needs that had hitherto been seen largely as the responsibility of health services.

In Chapter Eight I present my discussion and conclusions, bringing together the main themes that I see as overarching the case studies and the policy survey. I also discuss the limitations of my research and the implications for future research practice. I argue that the label of 'incapacity' constitutes Disability

and produces exclusion by denying people the resources for participation. I conclude that support for relationship and for participation is essential to achieve fairness, and I draw on the capabilities approach (Nussbaum, 2006a) to suggest why it is legitimate to provide additional support to maximise capacity. I conclude that the best safeguard for people who challenge services the most will be a recognition that everyone is vulnerable to incapacity to some degree, and that cognitive capacity is an inadequate basis for 21st century citizenship.

This research was conducted at the time of ‘The same as you? review of services for Scotland (also known as the Learning Disabilities Review). A decade further on, and with significant public expenditure cuts in prospect, the issues raised in this thesis remain pertinent to future policy and service development.

Personalisation and self-directed support offer opportunities to make services more flexible and individualised, and to bring the control over expenditure and service design closer to the person and their family. As such, these initiatives may respond to many of the problems with the funding and delivery of services upon which this research reports. However, whether they deliver better outcomes for people at most of risk of exclusion will depend on the framework within which they are implemented. If they become an instrument for levelling down costs, rather than improving outcomes, or for rewarding vocal consumers, rather than tackling inequalities, then they may further marginalise those who have hardly begun to experience social inclusion. This thesis argues that the funding and delivery of social care should prioritise participation and social inclusion as outcomes, and that this is more, rather than less important, for people who are furthest from attaining these outcomes. Moreover, the theory of inclusive citizenship will benefit from understanding the social conditions and practices that will maximise and safeguard the decision-making and communication capacities of all citizens.

Throughout this thesis I use the term ‘people with learning disabilities’ to be consistent with the terminology of public policy in Scotland and England. However I acknowledge that many members of self advocacy groups prefer to be called ‘people with learning difficulties’, in order to make the point that, although they may take longer to learn than others, that does not mean they cannot learn and develop. I have not adopted the phrase ‘intellectual disabilities’, which is used in the international academic literature, as it would

not be recognised by many people with learning disabilities in this country. I use 'Learning Disability' when I am referring to the field of practice concerning people with learning disabilities and employ capitals to make it clear that this is a departure from person-centred language for a specific reason. I have not provided a definition of 'people with learning disabilities' as I consider learning disability to be a spectrum within the population in which arbitrary categories have been created for a variety of social and administrative purposes. However, I believe that social practices create real barriers for people who need support to understand information, express themselves and take part in social relationships. I have not been able to avoid using the phrase 'people with high support needs', even though it refers to a very heterogeneous group of people and is a construct, not a measure of need. It does not describe who people are, but it does indicate situations in which service systems are challenged in their capacity to respond.

The names of all study participants have been changed and some identifying details altered.

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The Nuffield Trust funded my time during the fieldwork as part of their funding for the Nuffield Centre for Community Care Studies at the University of Glasgow and I gratefully acknowledge this support. The Board of the Scottish Consortium for Learning Disability (SCLD), chaired by Andrew Reid, allowed me to take essential study leave. I have also been fortunate in the support and encouragement I have received from the SCLD team and the many people we work with.

Dr. Alison Kerr took me to visit a long-stay hospital for people with learning disabilities and thereby showed me why I should see exclusion as my concern. Professor Alison Petch and Professor Colin Espie encouraged me to begin research with people with learning disabilities.

Many people have given me help along the way, including the administrative staff and other colleagues at the Nuffield Centre for Community Care Studies. I should particularly like to thank Lynn Stewart for her interview transcriptions and the interest she took in the work.

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In the background my husband John gave me love and the space to work, while providing an unending supply of food and commas. Thanks to him, I know what it feels like to be on the receiving end of emancipatory support. My daughter, Ruth, offered encouragement, cross-referencing and a model of what academic progress should be.

My deepest thanks are to the research participants. They enabled me to learn the meaning of a shared responsibility for social justice.

This thesis is dedicated to the memory of William Peter Menear, 'Pete', died 6th April 2009, aged 52 years.

Author's Declaration

I declare that, except where explicit reference is made to the contribution of others, that this dissertation is the result of my own work and has not been submitted for any other degree at the University of Glasgow or any other institution.

Signature

Printed name

Date

CHAPTER ONE Difference, Disability and Rights: The same as you?

1. Introduction

Since the 1990s the exclusion of people with learning disabilities from the rights and responsibilities of citizenship and social membership has been challenged in policies that have identified rights and belonging as the route to inclusion. In this vein in May 2000 the newly devolved Scottish Government published a review of services for people with learning disabilities called ‘The same as you?’. This had as its dominant theme the idea that people with learning disabilities should have access to the same opportunities to live an ordinary life as anyone else (Scottish Executive, 2000). In this chapter I will examine ‘The same as you?’ in the light of tensions between ‘sameness and difference’. Section 2 examines how ‘The same as you?’ was influenced by ‘ordinary life’ principles; it sets normative goals for a ‘good life’ for people with learning disabilities. The criticism of this position is that it does not allow sufficiently for diversity and for people with learning disabilities to have different aspirations. Section 3 considers ‘The same as you?’ from the perspective of the policy mechanisms in which it is embedded, principally a New Labour approach to equality of opportunities and social inclusion. I consider the arguments that this approach is inadequate to deal with inequalities and that its reliance on labour market participation may further exclude people who are unable to work or participate in conventional ways. As an alternative I consider the capabilities approach which provides for differential responses to human capabilities.

Section 4 takes up the argument about normativity and difference in relation to citizenship. It considers the extent to which norms of intellectual capacity and social independence are integral to Western theories and practices of citizenship and social membership. I argue that this leads to discrimination against people with learning disabilities and is a barrier to them accessing their civil and social rights. Learning Disability therefore provides a site for questioning the general claim that a citizenship framework can deliver inclusion and social justice for

disadvantaged groups. However practices of inclusive citizenship are increasingly engaging marginalised citizens in participatory initiatives to shape policy making.

Finally, Section 5 takes up the theme of difference and universalism in the context of Disability. I suggest that the historical tendency within learning disability services to classify people into categories demanded by particular service responses is not yet played out and may disadvantage groups of people with learning disabilities who have particular labels. I conclude by considering the possibilities for universalism *and* difference through equalities strategies based on appeals to human rights.

2. 'The same as you?' and 'ordinary lives'

This section describes 'The same as you?' policy and then considers the influences that shaped it, in particular the idea of the 'good life' developed from the legacy of normalisation.

'The same as you?' , the Learning Disability Services Review, was published at the beginning of May 2000, fulfilling the commitment made in the newly devolved Scottish Executive's Programme for Government to publish its proposals for learning disability services that year. The publication of the document had been widely anticipated because it had been preceded by a very wide public consultation that had included roadshows with people with learning disabilities and family carers, workshops, conferences, stakeholder groups, written and online consultation and expert papers. The involvement of people with learning disabilities had been particularly strong, with a 'user and carer' group among the main stakeholder groups.

The document itself was unusual as a policy document insofar as it was issued in large print, couched in straightforward language, and illustrated with photographs. Of the 29 recommendations in the Review, the most unequivocal target was that all long-stay hospitals should close by 2005, that areas likely to have hospital sites still open in 2002 should put in place joint plans for closure,

and that the number of long-stay beds should be reduced to between 1 and 4 per 100,000 population (recommendations 12-14). Local strategic development was to be focused through the production of joint plans, called Partnership in Practice Agreements (PiPs) (recommendation 1), supported by better planning information, collected by means of the controversial proposal to establish learning disability registers (Chapter Two). These agreements would include proposals for spending the Change Fund, which was to be made available to seed fund the changes proposed (recommendation 4). A Scottish Centre for Learning Disability was to be set up to provide information and public education (recommendations 6 and 21). The particular proposals that were intended to achieve a reorientation of services for people with learning disabilities and their families, enabling greater choice and wider opportunities, were access to a personal life plan for everyone who wanted one (recommendations 3 and 26), the appointment of local area co-ordinators to provide local information and support to be part of the community (recommendation 2), and access to direct payments (recommendation 5), which were expected to be mandatory by 2003. For services there was a strong emphasis on joint working, including that between general health services and primary care for people with learning disabilities (Chapter Six). It was envisaged that day services would be reoriented, with wider opportunities made available for lifelong learning (recommendation 15) and that local authorities and health boards would promote the employment of people with learning disabilities (recommendation 16).

This process of the Review had resulted in a change of focus, from primarily the provision of health and social care services, to better lives for people with learning disabilities, as a consequence of what the Review Team heard from people were their wishes and priorities. As the Minister for Community Care, Iain Gray, explained in the Ministerial Foreword:

This review began by looking at services, especially in social and healthcare, and their relationship with education, housing, employment and other areas. However, its focus changed to include people's lifestyles. That is what matters. Services are there to support people in their daily lives (Scottish Executive, 2000).

Therefore the relevant Chapter (Five), on 'A Full Life - What You Do', dealt not only with day services and short breaks, but with lifelong learning, employment, leisure and recreation, transport and public attitudes. There was also a strong focus on people being supported to have 'better choices, stronger voices' through accessible information, advocacy and communication support.

'The same as you?' was received as representing a widely shared view of aspirations for people with learning disabilities. However there were also disappointments. Its status was unclear; entitled a 'Review', it was neither a Green nor a White Paper and its recommendations remained only recommendations to local authorities and health boards, to the confusion of many who expected to see the changes implemented. An anticipated Action Plan was not included, so there was not a clear framework and timetable for national implementation. However the inclusive method of working used by the Review Team was maintained, as reflected in the composition of a National Implementation Group, while independent support for implementation was vested in the voluntary sector, through the newly formed Scottish Consortium for Learning Disability, which was also expected to work in an inclusive way. Some monitoring of progress by local authorities was put in place through the establishment of an annual statistics release. Further work to spell out the changes required in the health service was undertaken with the publication of a further policy document, 'Promoting Health, Supporting Inclusion' (NHS Scotland, 2002) and a Health Needs Assessment Report (NHS Health Scotland, 2004).

Across the four countries of the United Kingdom there were parallel attempts to set a new direction for services for people with learning disabilities (Whitehead et al., 2008). The strategy for England, 'Valuing People' was published in 2001 (Department of Health, 2001) and updated in 2007 (Department of Health, 2007b). In the 1980s Wales had been in the forefront of planning for comprehensive service development with the 'All-Wales Strategy' (Welsh Office, 1983). An enquiry into the challenges facing learning disability services in Wales at the beginning of the 21st century was published in 2001 (Learning Disability Advisory Group, 2001), although guidance from the Welsh Assembly Government came only in 2004 (Welsh Assembly Government, 2004) and it was not until 2007

that a new policy statement was published (Welsh Assembly Government, 2007). Stephen Beyer at the Welsh Centre for Learning Disabilities considers that the new statement affirms ‘ordinary life’ principles, but as in the Scottish policy, puts a greater emphasis on people with learning disabilities as decision-makers (Whitehead et al., 2008:7). In Northern Ireland an independent review of learning disability services, known as the Bamford Review, began in 2002 and involved widespread consultation. However its report, ‘Equal Lives’, was not published until 2005 (Northern Ireland Executive, 2005), and the Government response not until 2008 (Northern Ireland Executive, 2008). Implementation has not yet begun. According to McConkey (Whitehead et al., 2008:9), progress has been disrupted by service reorganisation, and by learning disability services being considered as part of mental health services.

These policies set a direction, rather than a detailed implementation programme. Jim Mansell (2008) contrasts this situation with earlier strategies, such as the 1971 White Paper, ‘Better Services for the Mentally Handicapped’ (Department of Health and Social Security, 1971). According to Mansell, all of the new policy statements were aspirational and visionary, a position not unconnected to their second most striking characteristic, viz. that their goals are not tied to resource allocation:

The vision set out is much more ambitious and comprehensive than official policy in the past. It is couched in terms, not of better services, but of equality and justice. It is also expressed in the broadest terms - as about enabling people to realize their civil and human rights in all aspects of their lives, and therefore as policy it has implications across government (Mansell, 2008:12).

The recommendations of ‘The same as you?’ are underpinned by a set of seven principles, in the same way that ‘Valuing People’ establishes four guiding principles of legal and civil rights, independence, choice and inclusion (Department of Health, 2001). The principles of ‘The same as you?’ reveal their pedigree in developments in thinking about services for people with learning disabilities over the previous two decades. The ideas being referenced include social role valorisation (SRV), as reflected in an emphasis on the importance of respecting and valuing people with learning disabilities, and ‘ordinary life’ principles, as indicated in the areas of lifestyles that they map out for attention.

According to Wolfensberger, whose ideas about human service reform were extremely influential in proposing standards for community-based living as an alternative to institutional solutions, the main problem to be addressed to improve the lives of people with learning disabilities was their status as a devalued social group (Race, 2003). In his analysis he was strongly influenced by contemporaneous social deviance theory, and in particular labelling theory, which posited that the behaviour of deviant groups was an outcome of societal reaction to their label and role. Changing cultural perceptions required the roles to be highly valued, not merely regarded as equivalent to the average. Thus Wolfensberger renamed normalisation, 'social role valorization' (SRV), a term which never came into widespread use in the UK (Wolfensberger, 1983).

The strategy that he proposed was to redesign community services on a systematic basis in a way that would provide socially valued roles for individuals with learning disabilities and so overcome their devaluation within the wider society (Emerson, 1992:6). Enhancing social roles had two aspects: enhancing image, the way that people were perceived, and developing their competencies. What this meant in practice for services and individuals is made explicit in the service evaluation tools, which were widely propagated through training workshops: PASSING (Program Analysis of Services System Implementation of Normalisation Goals) and PASS (Kendrick, 1999:428). In PASSING the quality of the service was scored according to its impact on the social image and competence of the people using the service. The desirable characteristics promoted by the training illustrate the assumptions it made about what constituted a valued (and devalued) life. The location of the service should 'look like the type of place valued people would have as a home'; it should not congregate people or bring them together with other devalued people; it should portray people in a positive light; and of daily life, the evaluator should ask, 'Does the service support its users in participating in valued activities, in valued settings, with valued citizens?' (Emerson, 1992:10).

In the UK the principles of normalisation became known through a series of papers on 'an ordinary life' produced by the King's Fund Centre (King Edward's Hospital Fund for London and King's Fund Centre for Health Services

Development, 1980 reprinted 1982, 1984, 1988) and through Tyne's adaptation of O'Brien's work (O'Brien and Tyne, 1981). The King's Fund Centre papers spelled out some of the implications of normalising the daily lives of people with learning disabilities through small residential services, employment opportunities and supporting the development of social relationships. These papers and their accompanying workshops began as an attempt to provide a new service model, because the 1970s had not seen significant increases in the numbers of people with learning disabilities living in small community-based facilities.

Also influential later were the Five Service Accomplishments of O'Brien (O'Brien and Lyle, 1987, O'Brien, 1989), who approached the issues from a commitment to people with severe disabilities and a strong emphasis on self-determination. He provided a framework for evaluating the outcomes of learning disability services for the people who use them. The Five Accomplishments are clearly founded in normalisation, but have a stronger emphasis on the choice of people themselves, and they reflect belief in the inherent value of people with disabilities. Both 'ordinary life' principles and the Five Accomplishments were practical and expressed in everyday language; as such they are direct predecessors of 'The same as you?'. Table 1.1 maps some of these connections.

Table 1.1 The principles of 'The same as you?' (SAY) compared with some antecedents

Theme - Social value

7 SAY Principles (Scottish Executive, 2000:11)	17 'Good things of Life' (Wolfensberger et al., 1996)	5 Service Accomplishments (O'Brien and Lyle, 1987)	An Ordinary Life (King's Fund, 1980)
People with learning disabilities should be valued. (1a)	To be viewed as human and treated with at least a basic level of respect by more than a few people. (9)	Enhancing the respect afforded to service users by developing and maintaining a positive reputation for people who use the service by ensuring that the choice of activities, locations, forms of dress and use of language promote the perception of people with disabilities as developing citizens. (4)	Mentally handicapped people [sic] have the same human value as anyone else and the same rights. (1)

Theme - Opportunity to contribute

7 SAY Principles (Scottish Executive, 2000:11)	17 'Good things of Life' (Wolfensberger et al., 1996)	5 Service Accomplishments (O'Brien and Lyle, 1987)	An Ordinary Life (King's Fund, 1980)
They should be asked and encouraged to contribute to the community they live in. (1b)	Being able to contribute and having one's contribution recognised as valuable. (16) Work and invested with more meaning than material gain (6)	Ensuring service users participate in the life of the community by supporting people's natural relationships with their families, neighbours and co-workers and, when necessary, widening each individual's network of personal relationships to include an increasing number of people. (5)	Not included as a principle.

Theme - Freedom from discrimination/harm

7 SAY Principles (Scottish Executive, 2000:11)	17 'Good things of Life' (Wolfensberger et al., 1996)	5 Service Accomplishments (O'Brien and Lyle, 1987)	An Ordinary Life (King's Fund, 1980)
They should not be picked on or treated differently from others. (1c)	Absence of imminent threats of extreme privation and violent death. (7) A reasonable assurance not to be a victim of gross injustice. (11)	Not included as a principle.	Not included as a principle.

Theme - Treat as an individual

7 SAY Principles (Scottish Executive, 2000:11)	17 'Good things of Life' (Wolfensberger et al., 1996)	5 Service Accomplishments (O'Brien and Lyle, 1987)	An Ordinary Life (King's Fund, 1980)
People with learning disabilities are individual people. (2)	Being treated as an individual. (12)	Not included as a principle.	Services must recognize the individuality of mentally handicapped people [sic]. (3)

Theme - Voice and choice

7 SAY Principles (Scottish Executive, 2000:11)	17 'Good things of Life' (Wolfensberger et al., 1996)	5 Service Accomplishments (O'Brien and Lyle, 1987)	An Ordinary Life (King's Fund, 1980)
People with learning disabilities should be asked about the services they need and be involved in making choices about what they want. (3)	Having a say in important decisions affecting one's life. (13)	Ensuring that service users are supported in making choices about their lives by encouraging people to understand their situation, the options they face and to act in their own interest both in small everyday matters and in such important issues as who to live with and what type of work to do. (2)	Not included as a principle.

Theme - Support to realise potential

7 SAY Principles (Scottish Executive, 2000:11)	17 'Good things of Life' (Wolfensberger et al., 1996)	5 Service Accomplishments (O'Brien and Lyle, 1987)	An Ordinary Life (King's Fund, 1980)
People with learning disabilities should be helped and supported to do everything they are able to. (4)	Opportunities and expectations to discover and develop abilities, skills, gifts and talents. (8) Good health. (17)	Developing competence of service users by developing skills/attributes that are functional and meaningful in natural community environments/relationships, i.e. skills and attributes which significantly decrease a person's dependency or develop personal characteristics that people value. (3)	Not included as a principle.

Theme - Access to mainstream, local services

7 SAY Principles (Scottish Executive, 2000:11)	17 'Good things of Life' (Wolfensberger et al., 1996)	5 Service Accomplishments (O'Brien and Lyle, 1987)	An Ordinary Life (King's Fund, 1980)
People with learning disabilities should be able to use the same local services as everyone else, wherever possible. (5)	Access to at least many of the sites of conduct of everyday life; not to be excluded from such place of human intercourse. (14)	Ensuring that service users are present in the community by supporting their actual physical presence in the same neighbourhoods, schools, work places, shops, recreation facilities and churches as ordinary citizens. (1)	Not included as a principle.

Theme - Access to specialist services

7 SAY Principles (Scottish Executive, 2000:11)	17 'Good things of Life' (Wolfensberger et al., 1996)	5 Service Accomplishments (O'Brien and Lyle, 1987)	An Ordinary Life (King's Fund, 1980)
People with learning disabilities should benefit from specialist school, health and educational services. (6)	Not included as a principle.	Not included as a principle.	Not included as a principle.

Theme - Services appropriate to needs

7 SAY Principles (Scottish Executive, 2000:11)	17 'Good things of Life' (Wolfensberger et al., 1996)	5 Service Accomplishments (O'Brien and Lyle, 1987)	An Ordinary Life (King's Fund, 1980)
People with learning disabilities should have services which take account of their age, abilities and other needs. (7)	Not included as a principle.	Not included as a principle.	Not included as a principle.

Theme - A Full life

7 SAY Principles (Scottish Executive, 2000:11)	17 'Good things of Life' (Wolfensberger et al., 1996)	5 Service Accomplishments (O'Brien and Lyle, 1987)	An Ordinary Life (King's Fund, 1980)
Not included as a principle.	Family or equivalent small intimate group. (1) A place you can call home. (2) Belonging to a small-scale social body. (3) Friends. (4)	Access to at least many of the ordinary activities of human social life, including their associated opportunities. (15)	Living like others within the community is both a right and a need. (2)

Theme - Other

7 SAY Principles (Scottish Executive, 2000:11)	17 'Good things of Life' (Wolfensberger et al., 1996)	5 Service Accomplishments (O'Brien and Lyle, 1987)	An Ordinary Life (King's Fund, 1980)
Not included as a principle.	A transcendent belief system. (5) To be dealt with honestly (10)	Not included as a principle.	Not included as a principle.

With acknowledgement to David Race who provided a similar table for 'Valuing People' (Race, 2004)

Some of the dimensions included in Wolfensberger's good life that are not present in the Review's principles - home, friends, meaningful work - are part of the Review's statements of what, in their terms, 'a full life' (Scottish Executive, 2000:38) should include. For example:

In future both children and adults with learning disabilities should, wherever possible, be supported to lead a full life with their families or in their own homes. Some people may be best in a setting which is not an ordinary house or rented by them or their family. But whatever it is, it should allow them to lead a full life and be included in society while providing privacy and allowing them to develop. Hospitals are not places where people with learning disabilities can live full lives. We asked someone we met in hospital what he wanted out of life. He said: "Somewhere to live, a job, some friends - the same as you really" (Scottish Executive, 2000:39).

The legacy of normalisation, though not referred to directly in either the Scottish or English policy documents, helps to explain why the 'The same as you?' focuses on changing the lifestyles of people with learning disabilities and the way that they are perceived and treated. The critique of normalisation is that it potentially devalues lifestyles that do not correspond to the norm, rather than seeking to change society to be more inclusive of difference and to overcome the barriers to participation that people with learning disabilities face. For example, normalisation discourages groups of people with learning disabilities from doing things together, but Brown and Smith (1992) point out that women's groups found that being able to meet together enabled them to resist the way that they felt silenced by culturally valued (male) norms.

However, the differences between the three lists in Table 1.1 are also of interest. 'The same as you?' has the strongest emphasis on self determination. It is pragmatic, rather than ideological, and does not reproduce many of the aspects of normalisation that have been criticised, such as, for example, failing to address the wishes and subjectivities of people with learning disabilities themselves. From the perspective of proponents of SRV, current policies are not robust enough in the mechanisms they adopt to ensure that people live valued lives. David Race, who has published a collection of Wolfensberger's writings, has compared the English strategy paper, 'Valuing People', unfavourably with SRV (Race, 2004). True, he finds similarities between the problems identified

by the two and the principles elaborated, although he sees a stronger emphasis on rights in the Valuing People principles. However he questions whether the actions proposed are strong enough to lead to changes in the service system likely to produce the outcomes desired on the grounds that rights alone will not deliver quality. Michael Kendrick, in a review of the impact of SRV, notes that there is a gap between the principles and the extent to which they have been fully implemented (Kendrick, 1999), a point echoed by Emerson (2005). Burton and Kagon (2006) also consider that 'Valuing People' represents a dilution of human service principles of enabling people to have the support necessary to be included by a neoliberal version of society and its membership. 'Ordinary life' principles had a strong emphasis on the support that people would need to be included.

Both the continuities and distance travelled since the 1980s can be seen in the conditions which Simon Duffy has identified as essential for people to take control of their own support (2006). His six 'keys to citizenship' include self-determination, direction (a plan for what you want to achieve), money, a home (base for life), support and a community life, defined as active engagement in the life of the community and an active network of relationships. Though set in a stronger context of choice and control they show continuing aspiration for the 'good life' for people with learning disabilities.

In the next section I consider the social policy framework in which 'The same as you?' is set and the tensions between equality and difference in approaches to social inclusion.

3. 'The same as you?' and New Labour policies on community care, public services and social justice

Whilst Learning Disability practitioners may have read 'The same as you?' with an awareness of the history of ordinary life principles, the context for 'The same as you?' was also provided by the attempts in the decade following the introduction of community care to modernise social and health services

throughout the UK. These attempts in turn can be seen as part of a wider adjustment of the relationship between the public sector and society. For example Osborne and Gaebler (Osborne and Gaebler, 1992) had argued that government through administrative bureaucracy was giving way to a stronger role for both markets and community, with government in a more strategic role. In this section I will examine the wider social policy and political context for the use of terms such as inclusion, equality, fairness, and opportunity in ‘The same as you?’.

The changes envisaged by ‘The same as you?’, notably closing long-stay hospitals and reforming day services, required changes in public services and in public investment. ‘The same as you?’ continued the main thrust of community care policy (Department of Health, 1989), to shift the balance of care from institutions into the community, to modernise services by making them more responsive to needs, and to improve joint working. Before devolution, the Scottish Office had recently issued a new action plan for community care, ‘Modernising Community Care’ (The Scottish Office, 1998), which sought to put new life into the agenda. In Scotland a higher proportion of expenditure on people with learning disabilities was devoted to long-stay hospitals (37% compared to 15% in England) (Scottish Executive, 2000:9), and this directly affected the availability of resources to develop community services. Spending on learning disability services at the time of the Review (£54 per person in the population in 1997/8) was less than in England (£59) or Wales (£63). There was therefore a strong financial, as well as moral argument for getting better value for money from shifting the balance of care. However lack of joint working and sharing of budgets was a barrier (Joint Future Group, 2000), and was feared to be a particular obstacle to the effective implementation of hospital closure (Stalker and Hunter, 1999), which had been a policy intention since 1993. The patchy nature of joint working between health, social work and housing across community care was to continue to be a focus for comment (Stewart et al., 2003, Petch, 2008) as implementation of ‘The same as you?’ got underway.

Despite devolution, the direction of policy for people with disabilities was little different in Scotland from England (see above). It has been argued that the realities of coalition government and the lack of freedom for manoeuvre in

public expenditure resulting from the Barnett formula¹, together with the continuity provided by the civil service, may have contributed to a lack of divergence in social policy in general (Parry, 2002, Midwinter, 2004, Viebrock, 2009); moreover differences between Scotland and England in public attitudes to welfare spending seem, on the basis of empirical research, to have been limited (Bromley et al., 2003). By contrast, the NHS in Scotland has continued on a distinctive path since devolution, particularly by having a more unified organisational structure than in England (Talbot-Smith et al., 2006). In health, as in social care, the principal difference between Scotland and England remains the lower penetration of market mechanisms in Scotland.

McRuer (2007) has highlighted the importance of being attentive to the contexts in which concepts such as inclusion are used; he argues that we become more aware of their limits by considering how they travel, that is, the work they do in different contexts. For example he suggests that when employed by World Bank advisers, the terms independence and inclusion function to obscure the wider dependencies imposed by neoliberal global capitalism. Social inclusion is defined in the ‘The same as you?’ as: ‘Helping people to feel and be part of the society in which they live. They are “socially included”’ (Scottish Executive, 2000:131).

The definition of inclusion in the parallel English paper, ‘Valuing People’ is similar, but with a stronger emphasis on access to mainstream facilities:

Being part of the mainstream is something most of us take for granted. We go to work, look after our families, visit our GP, use transport, go to the swimming pool or cinema. Inclusion means enabling people with learning disabilities to do these ordinary things, make use of mainstream services and be fully included in the local community (Department of Health, 2001).

In seeking to develop a policy that was consistent with the overall approach of the Scottish Labour and Scottish Liberal Democrat Coalition Government at the beginning of its 1999 - 2007 term, the authors of the Review sought to legitimate

¹ The Barnett formula is a mechanism by which a predetermined proportion of changes in the budgets for certain items of expenditure in England are automatically allocated to the Scottish Parliament, the National Assembly of Wales and the Northern Ireland Assembly.

their case by appealing to human rights and wider policy goals of equality, social justice and social inclusion. For example, in the Ministerial Foreword to the Review, the then Deputy Minister for Community Care in Scotland Iain Gray writes:

We are committed to improving the quality of life for people with disabilities. The review reflects our wider policies including social inclusion, equality and fairness, and the opportunity for people to improve themselves through continuous learning. These are just as important and just as relevant to people with learning disabilities as they are to all of us (Scottish Executive, 2000:iii).

Within Scottish policy therefore, ‘The same as you?’ was framed as part of the Labour-Liberal Democrat Government’s social justice strategy, ‘Social Justice, a Scotland Where Everyone Matters’ (Scottish Executive, 1999). This focused on social inclusion and equality of opportunity as strategies to tackle poverty (Scott and Mooney, 2009) and was to be followed in 2003 by the Scottish Government’s ‘Closing the Opportunity Gap’ (Scottish Executive, 2002, MacIntyre, 2008). These can both broadly be seen within the New Labour approach to social justice, which emphasised access to opportunity, autonomy and choice. Under the then UK Prime Minister, Tony Blair, there was an attempt to renegotiate the social contract underpinning the postwar welfare settlement in order to develop majority support for a more pluralist welfare state: the state’s role in welfare must be seen to benefit the majority rather than a minority (Giddens, 1998:108).

As an approach to reducing inequalities, New Labour’s social justice strategies have been critiqued, particularly on the left, from a number of standpoints. Lister and others have argued that the focus on inequalities of opportunity, rather than inequalities of outcome (Lister, 1998) and the primacy given to labour force participation as a mechanism to reduce inequalities (Jordan, 2001) will marginalise and further exclude those who may be unable to contribute productively, a particular concern for the inclusion of disabled people (Oliver and Barnes, 1998), but also for women (Williams, 2001). Abberley argued that if socially valued labour is seen as the only route to social inclusion, some people will become ‘peripheral’ because they participate in redistribution, but not in production (1996:69). Some see New Labour’s focus on deprived communities and the marginalised as an incomplete response to inequality because it focuses, and may therefore problematise, those experiencing inequalities, rather than

wider issues of the distribution of wealth and advantage within society as a whole (Lister, 2007c). The new welfare state social democratic principles were combined with an economic neoliberalism that has weakened their capacity to reduce inequalities (Scott and Mooney, 2009:384). Finally, the moral project of New Labour to equate citizenship with social contribution and responsibility has also been questioned because it may individualise responsibility and therefore reduce the overall shared responsibility of state and society to provide for those who cannot contribute (Lund, 1999). This leads to a narrowing of the public service agenda on to those services that the majority use, such as health and education. Clarke and Newman have traced the implications of these developments for the organisation of the welfare state. They argue that the power of new public sectors to manage public services is contested as new publics emerge to demand recognition of their claims (Clarke and Newman, 1997, Newman, 2002, Newman, 2007). Meanwhile 'the state's role shifts from policies of redistribution to those of enabling citizens to develop their capacities' (Newman, 2007:33).

Liberal theories of social justice also rely on choices made by rational and independent actors and it has been argued that this is another way in which exclusion is constructed and the inequalities of power obscured. Michael Davidson summarises the argument: 'Although liberal theories of social justice imply equal access to the public sphere, they do not account for individuals who, because of cognitive impairment or physical disability, cannot cooperate on "equal" and independent terms' (2007:55). Dependent relations, it is argued, explain why some are disadvantaged in the social contract (Kittay, 1999a). Dependency is othered by constructions of relations between independent equals as the norm (Davidson, 2007:59,65). In this way, caring work is gendered and devalued. A social contract which is thus incomplete, puts some people out of the reach of democracy and the benefits of productive relations. In sum, normalcy is embodied in social contract theory and welfare state theory. Fisher (2007) argues that one consequence of an individualised conception of citizenship, in which autonomy and independence are constructed as the norm, is a devaluing of groups involved in caring, such as the parents of disabled children. In their accounts, she finds an alternative understanding of autonomy and subjectivity which is constructed around 'being together' (Fisher, 2007:293).

Reinders also thinks that it is relationships with people with learning disabilities that are needed to overcome their exclusion: 'ultimately it is not citizenship, but friendship that matters' (2002:5).

The constituting of the active citizen as economically productive, empowered to exercise choice and enabled to participate through support to develop skills and capacities as part of a rhetoric of opportunity and social inclusion, may be double-edged for the inclusion of people with learning disabilities, as for other marginalised groups. While it may lead to an emphasis on progressive strategies, such as those to increase access to lifelong learning and employment, it may also represent an over-reliance on individual effort and choice as policy mechanisms to tackle exclusion. The capabilities approach, developed by Nussbaum (2006b) from the work of Sen (2009) provides an alternative to the presumption of relations between independent, rational individuals as the basis of social justice. Nussbaum has attempted to address the problem that Rawls' theory of the primary contract cannot provide a basis for securing the rights to a dignified life of people whose mental capacity is limited. The capabilities approach, by contrast, offers a framework for the evaluation of policy and practice according to 'what people are effectively able to do and to be' (Robeyns, 2005). Nussbaum rejects the Kantian definition of personhood as based in reason and sentience. By defining 'the good' as opportunities for flourishing, she does not attempt a comprehensive definition of the good life and is therefore able to allow for different ways in which people may wish to attain dignity. Nussbaum proposes that justice requires us to specify some core entitlements for everyone, i.e. a minimum threshold for enabling justice. These entitlements represent the conditions under which flourishing is possible. But how that flourishing happens may be different for different people.

In the next section I consider how assumptions behind some citizenship practices can discriminate against people with learning disabilities.

4. Citizenship

‘The same as you?’ suggests that if people with learning disabilities enjoyed the same rights as ‘their fellow citizens’ their lives would be better. In fact the word ‘citizen’ only appears three times in the review, other than in relation to citizen advocacy. Each time the reference concerns the rights which other citizens enjoy and which should be extended to people with learning disabilities. Thus, for example, they would be enabled to take appropriate risks, rather than being over-protected:

Many of those we interviewed during the review told us that too much time, money and energy was spent on over-protecting people with learning disabilities. As ordinary citizens we can make many decisions about the risks we take in our lives (Scottish Executive, 2000:78).

Thus the life enjoyed by the ‘ordinary’ citizen is the benchmark and it is argued that, on grounds of fairness and justice, people with learning disabilities should have access to equivalent rights. The wider citizenship literature would suggest that there are risks in employing an image of the ‘ordinary citizen’ as the basis for achieving the inclusion of any marginalised group. Citizenship can be the vehicle by which the limits to inclusion and belonging are prescribed. Isin and Turner point out that citizenship has always contained both exclusionary and inclusionary potential: ‘Thus, while cast in the language of inclusion, belonging and universalism, modern citizenship has systematically made certain groups strangers and outsiders’ (2002:3).

They cite the first definition of citizen as a city-dweller, by which the rural pagan was deemed excluded from rights and the acquisition of culture and its recognition (Isin and Turner, 2002:5). Policy and legislation aimed to promote and secure the civil rights of disabled people has been analysed to reveal its underpinning assumptions about the ‘normal’ citizen and the corollary of who is constructed as the excluded ‘other’. Feminist political theorists have shown how the exclusion of women is inscribed in a concept of citizenship that ignores gender differences (Lister, 2007b:51) and that the classic citizen subject is not as universal as he seems (Mouffe, 1992, Young, 2000, Lister, 2003). For example:

The universalistic cloak of the abstract, disembodied individual has been cast aside to reveal a definitely male citizen and a white, heterosexual, non-disabled one at that (Lister, 2003:68).

Disability theorists have claimed that civil rights do not provide a sufficient basis to tackle the inequalities that disabled people experience because they do not necessarily ensure access to the social rights needed to enable them to access the means to overcome these (Morris, 2005). Young and Quibbell (2000) argue that rights alone will not secure justice for people with learning disabilities because formal rights are based in expectations of individual autonomy and do not provide the means for powerless groups to contest their disadvantage.

The citizenship of people with learning disability raises issues of competence and independence that are central in modern western formulations of citizenship and social membership. In Western democracies, the capacity for independent decision-making is built into democratic and political systems as the basis for participation. This has the potential to present particular barriers for people with learning disabilities to access justice through formal citizenship and indeed in most countries they are disadvantaged in access to political rights. Beckman (2007) writing in a Swedish context, but addressing Western democratic political theory, suggests that the primary reason for the disenfranchisement of people with cognitive impairment is not only lack of capacity, but also the concern that they will not exercise independent political judgement either in choosing political preferences or in voting itself. He argues that independence (or autonomy) has been seen since Rousseau as essential to the integrity of the democratic process in order to ensure the equal distribution of political influence:

The ability to act independently is believed to be an essential quality of the democratic citizen. The best reason for insisting on independence is that it remains a condition for protecting the political equality of all citizens. To the extent that the preferences and the voting behaviour of people with intellectual impairments do not express their own judgements, they accordingly undermine an essential feature of democratic elections (Beckman, 2007:21).

Beckman puts forward the counter claim that political equality requires opportunities for effective participation. Rather than disenfranchising people who need support to understand information or actually to vote, he suggests the

provision of that support, with appropriate safeguards. The fact that some people will still not have the capacity to participate is no reason to remove their right to do so.

The experience of people with learning disabilities with respect to the justice system evidences the practices that can follow from a competency-based view of the independent, legal subject (Talbot, 2007). In Scotland the Mental Welfare Commission reported in 'Justice Denied' how a woman with learning disabilities who was not able to be a credible witness was not able to have her alleged abuser brought to court and had her own life restricted for her protection (Mental Welfare Commission, 2008). The UK-wide study of offenders by the Prison Reform Trust, appropriately entitled 'No One Knows', points out that offenders with learning disabilities are also unlikely to be referred to treatment programmes because these rely on verbal capacity (Talbot, 2007). These indicators of unequal treatment before the law indicate uncertainty about the capacity of people with learning disabilities as legal subjects. There are procedural reasons why people with learning disabilities may be denied justice both as suspect and victims. The principle of a fair trial can be seen as an obstacle to permitting intermediaries to enable people to have their capacity as defendants or accused, supported in court. Nonetheless, following successful evaluation of pilot projects, intermediaries have been rolled out successfully in England since June 2007 (Plotnikoff and Woolfson, 2007). In Scotland, the Vulnerable Witnesses (Scotland) Act 2004 provides for a range of methods, including video links, to enable children and vulnerable witnesses to give their evidence in safe environment (Patrick and Smith, 2009).

However recent work on citizenship has suggested that, like theories of social justice, a more inclusive framing is possible which takes cognisance of both universalism and difference. In order to address the problems inherent in liberal citizenship many writers are proposing a differentiated view of citizenship that acknowledges fluid and cross-cutting experiences of inequality (Isin and Turner, 2002). Lister (Lister, 2007b) draws on the work of Kabeer, who identifies universal values that should underpin citizenship from the accounts of excluded people in the South. These are justice (fairness, equivalence),

recognition (dignity, respect), self determination (control) and solidarity (collective action), (2005:3-8). Recognition in this context means respect for being of equal worth and therefore includes acceptance of difference. In contrast to the 'ordinary citizen' in 'The same as you?' Kabeer endorses a radical pluralist view of citizenship as proposed by Young (1990a).

In her work on the relationship between inclusive citizenship and social justice, Lister (2002, 2007a, 2007b) argues that citizenship must address power as well as economic disadvantage, recognition as well as redistribution, and that the cultural, political and economic aspects of citizenship must all be present to achieve social justice (2002). Lister considers involvement in decision-making, including the possibility to influence the policy process, as essential for inclusive citizenship and employs Fraser's concept of 'participatory parity' that embraces both individual voice and institutional patterns of cultural value (Lister, 2002). For Lister, such engagement represents the political aspect of citizenship without which policy proposals will fail to address the real issues that people face. Thus participation is necessary for citizenship to contribute to social justice. Attending to the perspectives of people living in poverty, and in particular those who participated in the Commission on Poverty, Participation and Power, she argues that respect is a priority for people who are marginalised and that cultural citizenship, respect for who someone is, matters (Lister, 2007a). Cultural citizenship is not an assertion of identity politics, but an aspiration that everyone should be valued and differences respected (Stevenson, 2001, 2003). As Lister explains, the theoretical and practical challenge is to find a way of retaining universalism as a basis for challenging inequalities, while embedding difference within it.

Young (1990a) argues that distribution alone will not achieve justice for disadvantaged social groups because oppressive relations are embedded in social structures and processes that in turn restrict the conditions for empowerment. Social justice, she argues, requires action to enable people to exercise self determination, to participate and to develop their capacities: 'A person has opportunities if he or she is not constrained from doing things, and lives under the enabling conditions for doing them' (Young, 1990a:26).

‘The same as you?’ declares that ‘people with learning disabilities should be helped and supported to do everything they are able to’ (Scottish Executive, 2000:11). It is also concerned about the ways that people with learning disabilities are seen by others and recommends a programme of public education to improve public understanding. Its agenda, therefore, connects closely with Young’s stress on the cultural conditions for overcoming oppression. She writes:

People have or lack self-respect because of how they define themselves and how others regard them, because of how they spend their time, because of the amount of autonomy and decision-making power they have in their activities and so on ... Self-respect is at least as much a function of culture as it is of goods ... (Young, 1990a:27).

Thus cultural rights, that is, rights to non-stigmatising and undistorted representation (Stevenson, 2001:3) are part of the claim to greater fairness that can be made by people with learning disabilities. In ‘The same as you?’ enabling participation and challenging oppressive social relations are seen as essential strategies for overcoming the inequalities and exclusions experienced by people with learning disabilities. Whilst liberal citizenship theory emphasised the vertical relationship between the state and the individual, more recent writing gives greater prominence to the horizontal relationships between citizens and groups (for example, Kabeer, 2005:23). This is actually the position taken in ‘The same as you?’, which cites the United Nations Declaration on the Rights of Disabled Persons (1975) that disabled people have the same fundamental rights as their fellow citizens of the same age, which implies first and foremost the right to enjoy a decent life, as normal and full as possible (Scottish Executive, 2000:2). The text of the Review which immediately follows this quote suggests that it is relations between citizens that are the primary concern and that rights and responsibilities need to be considered in the context of social inclusion:

People with learning disabilities have always been part of society. Sometimes they have been treated well, and sometimes they have been treated in ways that are unacceptable. Sometimes what seemed the best approach has, looking back, appeared lacking in understanding. More disturbingly there have been some well-documented serious instances of abuse. Always it has been a matter of how people deal with one another. There are important issues of human rights, responsibilities and social inclusion that we all need to look at if progress is to be made (Scottish Executive, 2000:2).

A rights-based framework by itself is unlikely to lead to social justice for all people with learning disabilities unless it addresses the gaps and inequalities in mainstream citizenship norms which otherwise will continue to create social inequalities for people who are marginalised by them. A fairer experience requires attention to the social and cultural norms of citizenship as well as to the distributive impact of current policies. The ambitions of ‘The same as you?’ to reduce the inequalities experienced by people with learning disabilities may therefore be more effectively supported by a pluralistic view of citizenship that embraces, political, cultural and social aspects and accepts the normative nature of expressions of citizenship.

5. Disability and difference

In order to argue for equality of opportunity, ‘The same as you?’ suggests that people with learning disabilities have the same goals for their lives as anyone else in society, but experience specific barriers to attaining them. Hence the question mark in the title of the report. In this section I explore further the theme of sameness and difference from the perspective of Disability theory and I consider the prospects for universalist perspectives. In order to do so I consider three perspectives on Disability: as a signifier of difference, leading to exclusion; as a minority status that reveals inequalities; and, as an identity and lived experience. I consider these perspectives with particular reference to the lives of people with learning disabilities.

5.1. Disability and exclusion

The social model of disability explains the exclusion experienced by disabled people as a function of the social barriers which ‘render people with impairments dependent and unable to engage in many social and economic activities’ (Barnes et al., 1999:79). Materialist barriers have been the primary focus of many social model theorists in explaining the operation of social oppression, but the disabling effects of the construction of disabled people as

culturally 'other' also forms part of the analysis (Priestley, 1998). Indeed Paul Hunt, one of the earliest UK disability activists, identified the issue as the way that disabled people were devalued by others in society, set apart and constructed as 'useless' (Barnes et al., 1999:77). Studies of cultural representation have shown how difference has been inscribed, and 'normality' legitimated, through portrayals of the disabled body as freakish and monstrous (Garland Thomson, 1997).

U.K. legislation provides disabled people with the means of redress against discrimination and promotes their civil rights. The Disability Discrimination Act 1995, amended 2005, renders discrimination illegal on grounds of disability in employment, education, access to goods, facilities and services, buying or renting land or property and the ways that public bodies exercise their functions. Research on the views and experiences of people with learning disabilities in Scotland in relation to Part 111 of the Act (access to goods, facilities and services), found that their awareness of the relevance of the Act to their lives and willingness to challenge discrimination was variable, even though many had experienced unfair treatment which had caused them distress (Stalker and Lerpiniere, 2009). The authors conclude that there is a need for awareness-raising about the Act with people with learning disabilities and for training for staff in service provider organisations in how to respond effectively to the needs of people with learning disabilities in order to ensure their fair access to services. Lack of accessible information is a significant reason for unequal access amongst people with learning disabilities (Walmsley, 2010). Indeed, Seale and Nind (2010:11), explaining access issues as they affect people with learning disabilities, consider access to be a multidimensional process which includes physical access, knowledge, power, relationships and communication, advocacy, participation and quality of life ('belonging, enjoying, benefiting').

The Disability Equality Duty which came into force in 2006 was intended to change the culture of the public sector and places a responsibility on public bodies to: promote equality of opportunity between disabled people and others; eliminate unlawful discrimination; eliminate harassment of disabled people related to their disabilities; promote positive attitudes towards disabled people; encourage participation by disabled people in public life; and, take steps to take

account of disabled people's disabilities, even where this means they may receive more favourable treatment than others. In 2008-9 a review of general healthcare services across Scotland found that engagement with people with learning disabilities was uneven among health boards and recommended that NHS staff needed more training in their responsibility to promote equality (NHS Quality Improvement Scotland, 2009). The NHS Quality Improvement Scotland report identified indifference as the main source of discrimination for people with learning disabilities, but overt hostility and even violence are also part of the daily experience of many people with learning disabilities. A study conducted for Capability Scotland and the Disability Rights Commission in 2004 found that one in four of the respondents with learning disabilities in Scotland reported an incident of hate crime, that is being frightened or attacked because of their disability, at least weekly (Higgins, 2006). The Offences (Aggravation by Prejudice) (Scotland) Act 2009 now provides a means to tackle hate crime that occurs on grounds of disability, sexual orientation or transgender status. Information and attitudes are therefore amongst the specific barriers that people with learning disabilities encounter to accessing equal treatment and it is important that attempts to counter discrimination take these into account, although without further labelling people with learning disabilities in the process.

The impact of discrimination through attributions of a negative identity is particularly evident in the history of people with learning disabilities. People with learning disabilities have been both depicted and treated as 'other' in a way that has excluded them from society. Chapter Two of this thesis describes in more detail how deviance theory, and related attributions of stigma as a cause of exclusion, was influential in early research on people with learning disabilities. The history of services for people with learning disabilities in the United Kingdom shows how labelling has been used to justify their incarceration and control. David Race has demonstrated how the categories developed supposedly to describe the needs of people with learning disabilities have been subjective, and influenced by the administrative imperative to define the services that people could receive (1995). Fear of social disruption was a major influence on the creation of the category of 'feeble-mindedness'. The 1913 Mental Deficiency Act was influenced by eugenic thinking and segregation was

legitimated through medical assessments. One of the functions of the residential institution was to protect society from socially disruptive behaviour, and therefore people were admitted because of challenging behaviours as well as severity of impairment.

In an exploration of the hidden history of services in the community for people with learning disabilities between 1913 and 1946, Walmsley and Rolph (2001) show how the 1913 and 1927 Mental Deficiency Acts created a framework in which care in the community was defined in relation to institutional care. The role of the family was to provide 'effective control' and families were subject to surveillance to determine whether they were keeping the dangerous impulses, particularly sexual, of a person within their care under control. Race shows that even the National Development Team classification of 1978 of people with learning disabilities into four groups of people, a classification that sought to avoid labelling, still dealt with categories of services, not needs, and was concerned to express who, according to the effects of their impairment, should or should not be in hospital (1995).

As a label, therefore 'learning disability' has been particularly subject to manipulation according to social concerns. Davis (1995) has charted the emergence of the concept of the norm in statistics and literature in the mid-nineteenth century and the relationship of the first statisticians to eugenics. He shows how intelligence came to be ranked into quartiles; the cut-off below which intelligence was considered 'subnormal' was therefore supposedly determined by statistical considerations, although the symbolism of 'deviance' was far more profound.

There is still some ambivalence about including all people with learning disabilities within a social model perspective. In part this is because those who have benefited least from recent policy are those with the most profound impairment effects. The term 'impairment effects' was introduced from within a social model perspective by Thomas (1999) to make it possible to take account of the fact that impairments can have real effects, for example, pain. The October 2009 issue of the Tizard Learning Disability Review is devoted to 'making it happen for everyone' and in the editorial Mansell comments that

‘people with learning disabilities who have complex needs have missed out on the benefits of the new policy [Valuing People]’ (Mansell, 2009). People with complex needs are also the priority for the second phase of implementation of ‘The same as you?’ The term ‘complex needs’ is used to include people with profound and multiple impairments who have complex health needs and also people who pose other additional challenges to services, such as people with behaviours that challenge services.

An earlier special edition of the Tizard Learning Disability Review in April 2001 had been devoted to arguing the case for attention to the needs of ‘people with PMLD’ (sic). The term is there taken to refer to people with profound intellectual impairment and other impairments:

The combination of profound intellectual impairment and additional physical and/or sensory disabilities can result in an individual needing significant support to engage with the environment and with others’ (Carnaby, 2001:2).

At about the same time (August 2000) a special interest research group on ‘PMLD’ was formed within the International Association for the Study of Intellectual Disability (IASSID). Profound impairment receives less attention in ‘The same as you?’ than complex needs, featuring mostly in a section on day opportunities. Paragraphs 61 and 62 explain them as follows:

The terms “profound and multiple disabilities” or “profound and complex needs” have replaced terms such as “special care” and “profoundly handicapped” and are seen as recognising the very specific needs of this group. As well as profound learning disability, people will have other physical disabilities and sensory impairment or both. Most will also have significant healthcare needs. 66% will have severe epilepsy, most will have difficulties in eating and drinking, and problems with their breathing. As a result, services should meet this range of needs’ (Scottish Executive, 2000) (p.92).

Complex needs is used to mean a need that is additional to the learning disability and in the glossary is defined as: ‘the needs that a person has over and above their learning disability. For example, extra physical or mental health problems, challenging behaviour or offending behaviour’ (Scottish Executive, 2000) (p. 128). The review cites a range of circumstances from which ‘complex needs may arise’ (para.46). The full list given in the review is:

- significant difficulties with communication, moving about or physical or social development;
- the complicated nature of support and services needed to help a person with learning disability cope with mental health problems, or getting into trouble with the law;
- the difficulties for the person or families, carers and others caused by people who injure themselves, who are aggressive or destructive or who display socially-unacceptable behaviour or other challenges;
- the extraordinary services that may be needed to cope with unusual or rare conditions; and,
- specific medical problems such as epilepsy, disruptive or disordered sleeping patterns, problems with eating and poor physical and mental health (Scottish Executive, 2000)(p. 87).

These two categorisations (PMLD and complex needs) suggest processes at work within services to establish the case for unmet needs. On the one hand there is a concern that the distinctive health needs of people with profound impairments may be overlooked by non-specialist services. On the other a heterogeneous category of people with additional needs is being created. The composition of this category is closely related to the history of specialist services for people with learning disabilities in the UK. Could it be that 'people with complex needs' constitute the remit of future specialist services? Another reading could be that learning disability itself is no longer sufficient to justify support and that, ironically, residual learning disability services will be funded on the basis of needs that are both additional to the learning disability services and not met by any other service. At the least the existence of these categories suggests that the process of differentiating groups of people with learning disabilities according to the services they may require still continues.

5.2. Disability as minority status

The legacy of labelling as a method of control over people with learning disabilities is a powerful influence on how self advocacy groups such as People First view the importance of being able to speak for themselves and determine their own futures. The individual and collective views and experiences of self-

advocates with learning disabilities², are increasingly reaching the public domain (Apsis, 2000, Mitchell et al., 2006). Therefore for some people learning disability is being embraced as a minority identity, in common with other marginalised groups, although the relationship of self advocacy groups of people with learning disabilities with other groups of disabled people is not unproblematic (Walmsley, 2005), as is illustrated by their preference for 'person first language' ('people with learning difficulties, rather than 'disabled people'). The term 'people with learning difficulties' represents a reaction to the history described above, and is intended to make it clear that, given time, everyone can learn. It was, for example, People First members in Scotland who challenged the prohibition on voting of people in long-stay institutions and succeeded in changing the law.

The perspective of people with learning disabilities as a minority group is increasingly reflected in appeals to human rights in order to challenge the inequalities experienced by people with learning disabilities, particularly in access to health care and justice. A report by the Joint Committee on Human Rights (2008), 'A Life Like Any Other?' concluded that their evidence showed that people with learning disabilities were more liable to social exclusion, poverty and isolation and that their disadvantage should be acted upon in the light of the human rights principles of dignity, equality, respect and autonomy. Ward and Stewart (2008) reassert the value of rights as protective of the agency and dignity of people with learning disabilities. They argue that rights obligate others to develop the skills and create environments that can increase the capacity of people with learning disabilities to achieve their goals. In England, case studies of six preventable deaths were highlighted by MENCAP in order to demonstrate how general health care was failing people with learning disabilities (MENCAP, 2007) and the issues were also investigated by the Disability Rights Commission (Disability Rights Commission, 2006b). The campaign led to an Independent Inquiry, which recommended a wide range of changes to tackle systematic discrimination (Michael, 2008). In Scotland Fatal Accident Inquiries into the deaths of James Mauchland (Sheriffdom of Tayside Central and Fife at Dundee, 2003) and Roderick Donnet in 2003 (Sheriffdom of

² I acknowledge that 'people with learning difficulties' is the term preferred by self-advocates and retain the term 'people with learning disabilities' only for consistency (see Preface)

Tayside Central and Fife at Dundee, 2007) highlighted similar neglect and led to instructions to health boards to produce action plans that have been reviewed by NHS Quality Improvement Scotland. In Scotland's action plan for health inequalities, people with learning disabilities have been included as a 'vulnerable group' for whom special reassures are required to reduce inequalities in access to health care (Scottish Government, 2008).

Consideration of people with learning disabilities as a minority group with claims to equal treatment raises the issue of how far all forms of disability inequality can be addressed as part of a wider equality agenda, or whether specific equality strands require specific measures. The final report of the Equalities Review, 'Freedom and Fairness' (Equalities Review, 2007) draws on the capabilities approach and human rights frameworks in an attempt to acknowledge difference in its definition of equality. The definition incorporates ideas of positive freedoms, support to overcome barriers and the attainment of desired goals:

An equal society protects and promotes equal, real freedom and substantive opportunity to live in ways people value and would choose, so that everyone can flourish. An equal society recognises people's different needs, situations and goals and removes the barriers that limit what people can do and can be (2007:16).

According to Sylvia Walby and colleagues, by allowing for the fact that different people may want different outcomes, 'this approach locates diversity, difference and choice at the centre of the framework' (2008:9). The 10 dimensions of equality identified in the equalities framework are shown in Table 1.2.

Table 1.2 Dimensions of equality

Equality Dimensions	(Walby et al., 2008)
longevity	avoiding premature mortality
physical security	freedom from violence and physical and sexual abuse
health	well-being and access to high quality healthcare
education	being able to be both creative, to acquire skills and qualifications, and having access to training and life-long learning
standard of living	being able to live with independence and security, and also including nutrition, clothing, housing, warmth, utilities, social services and transport
productive and valued activities	such as access to employment, a positive experience in the workplace, work / life balance, and being able to care for others
individual, family and social life	including self-development, having independence and equality in relationships and marriage
participation and voice	including participation in decision-making and democratic life
identity, expression and self-respect	including freedom of belief and religion.
legal security	equality and non-discrimination before the law and equal treatment within the Criminal Justice System

The framework addresses the areas of discrimination which I have highlighted as affecting people with learning disabilities. However, home and friendships, two dimensions most often stressed by and for people with learning disabilities (see Table 1.1) are not emphasised, while arguably one key aspect, highlighted in this Chapter, that of inter-relatedness, is not present.

5.3. Disability as identity and lived experience

If there are tensions between disability-specific and a wider equalities approach, there are also questions about the extent to which many people with learning disabilities acknowledge a disabled identity and an identity of learning disability in particular. A study in Wales found that parents sometimes chose not to tell their son or daughter that they had a learning disability because they saw this as a negative identity. However some people with learning disabilities did internalise lower expectations of what they could do and their lives would be like (Davies and Jenkins, 1997). The identity of a disabled person is not necessarily accepted by other disabled people either (Watson, 2002).

Recent work has examined the tension between sameness and difference in disabled identities. Beckett attempts to bring the experience of disability to bear on the issue of citizenship and he concludes that citizenship is best thought of as a process of engagement with human rights at its heart (Beckett, 2006b). He arrives at this conclusion in part by considering Turner's thesis (2006) that a shared awareness of vulnerability can transcend divisive categories and create a basis for shared responsibility. This is a theme taken up by Shakespeare (2006), who now sees disability, not as a segmented identity, but as a universal and shared identity, that may have the potential to rekindle solidarity across different equalities groups.

6. Conclusion and research questions

I have traced the origins of 'The same as you?' and also examined its position amongst social justice strategies in the devolved Scotland and social welfare policies more generally. People with learning disabilities are disadvantaged by the assumptions of liberal citizenship, justice and social contract theories that are dependent on assumptions of rational choice by independent actors. There are therefore risks that the current policy framework contains the seeds of exclusion for people who do not conform to the aspired-for norm of productive,

included citizens. However pluralist theories of citizenship challenge these assumptions, and a theory of social justice, based on the capabilities approach, makes it possible to envisage the distribution of social goods to reduce inequalities in the resources available to different groups to participate.

I considered some issues of disability and difference and the relevance of these to understanding the position of people with learning disabilities. I identified that there were tensions even within the policy of inclusion for people with learning disabilities and suggested that those considered to have the most severe impairments or to be challenging the capacities and boundaries of service provision and whose needs were not being met well by current provision might be the focus of struggles over professional power and debates over the scope of inclusion. Three arguments are made about the 'ableist' nature of inclusion discourse in western public policy in the last two decades of the twentieth century. The first is that disabled people are constituted as a social problem to be dealt with, thus suggesting that they are 'other' and on the margins of society and citizenry. The second is that strategies to include disabled people reveal the ableist basis to the construction of the good citizen - active, independent, productive. Thirdly, the proposed solution of inclusion represents a technology of control that, by demanding conformity through, for example, employment and public participation, seeks to normalise disability and make disabled people as little different as possible. In this thesis I am particularly interested in how these discourses may lead to the further identification, exclusion from civil and social rights and control of people who are not perceived as being able to be 'the same as you'.

Section 2 of this chapter identified the need for people with learning disabilities to have more say over the kinds of life they want to live. It also suggested that normative assumptions of the 'good life' may make it harder for people with learning disabilities to obtain the support they need to live fulfilling lives. For these reasons it is important that research explores the perceptions of people with learning disabilities themselves and how they experience the processes of exclusion and inclusion in their daily lives. Moreover, people with profound impairments and other complex needs are least likely to have their wishes and experiences included in consultations, service evaluations and research. It is

on this basis that I formulated the first research question for this study, which asks: what does home and belonging mean to people with learning disabilities who have high support needs and how do they experience the processes of inclusion and exclusion in their daily lives?

A concern to ground theorising about citizenship in the lived experience of citizens has also been expressed in the wider citizenship literature. Lister notes the need for more empirical studies to underpin theoretical debates about the meaning of citizenship:

The field would be enriched by more empirical studies of “the everyday world of citizenship” (Desforges et al, 2005); of the cultural, social and political practices that constitute lived citizenship for different groups of citizens in different national and spatial contexts (Lister et al., 2007) and of how citizenship’s inclusionary/exclusionary dynamics are experienced by both citizens and non-citizens (Lister, 2007b:58).

Kabeer, whose own edited volume addresses the meanings and expressions of citizenship from the standpoints of excluded people across the world, echoes the need to understand the relationship between the meaning of citizenship to people who are marginalised and aspirations for a more inclusive society:

We do not know what citizenship means to people - particularly people whose status is either non-existent or extremely precarious - or what these meanings tell us about the goal of building inclusive societies (2005:1).

My study of the experiences of people who live at the boundary of inclusion by society and learning disability services provides a critical lens through which to examine the meaning of citizenship beyond the existing norms of independence, productive work and civic participation.

There is also a methodological aspect to this chapter’s theme about whether mainstream or specialist approaches, ‘ordinary’ means or strategies to achieve differential justice are most likely to lead to equality for people with learning disabilities with additional needs. People with learning disabilities have asserted their rights to know about research and be active participants in it and there is a growing tradition of inclusive research that seeks to work alongside people with learning disabilities to develop research that is relevant to their

lives, informed by their participation, and capable of being used to improve their lives. However, the collaborative nature of research between researchers and people with limited access to the levers of power provided by institutionalised formal knowledge raises important issues of ethics, power and ownership that I examine further in the following Chapter. When people cannot directly tell their own story, the power of the researcher to interpret their meanings and experiences is magnified (Barnes, 1996a) and the balance between advocacy and appropriation is a constant tension. In this study I wanted to find out to what extent the perceptions and experiences of people with profound cognitive impairments, limited speech, or other additional needs could be explored using qualitative research approaches, thereby giving rise to my second research question. Were the issues in such research different in kind or only in degree? What were the qualities and competencies required of ethical and effective research practice in this area? An agenda of protection was emerging in legislation about research with people with incapacity, and in my research I wanted to explore whether this could be balanced with benefits from the process and outcomes of research participation.

In the past, the lives of people with learning disabilities have been subject to control and segregation through legislation and service philosophies that have deemed them incapable of adult responsibilities and ineligible for the signifiers of social citizenship, such as home, family, and a job. According to Disability theorising, such exclusions reveal the assumptions and fears of mainstream society (Burch and Sutherland, 2006), just as the term ‘learning disability’ may highlight the value and importance accorded to learning and qualifications in the knowledge society (Dumbleton, 1998). Whilst, therefore, current policy goals for people with learning disabilities emphasise rights, citizenship and inclusion, it is not cynical to ask who is most likely to be left out of a world constituted by norms of productivity and participation. Could inclusion create a new normalcy through which those people with learning disabilities who could most easily be accommodated by policies of mainstreaming become better able to access their social rights, whereas others, who challenge those same norms, fall further behind? My third research question therefore aimed to explore the discourses of inclusion amongst the people with responsibility for recommending the allocation of resources and developing services for people in Scotland. How did

they understand inclusion? Did they or did they not see it as their responsibility to take steps to challenge the 'rules of the game' (Northway, 1997) and find ways to include in the community people who challenged services the most? Specifically, I wanted to know who, if anyone, they thought marginal for inclusion and whether there would be a correspondence between this group and people who have always been least likely to receive services in their local area, for example because their behaviours challenged the capacity of services (Department of Health, 1993, Department of Health, 2007a).

Thus this work started from the basis that inclusion and access to social rights are not the inevitable result of improved policy frameworks for people with learning disabilities, and that it is important to analyse both how far their experiences and wishes match policy intentions and also what conditions are required to prevent a widening of inequalities. I began, and end, with the belief that those who are most marginalised and excluded have the most to teach on these subjects.

CHAPTER TWO Power, Positioning and Participation in Learning Disability Research: Issues for inclusive research methods

1. Introduction

In this chapter I consider the epistemological, ethical and methodological issues posed by research with people with learning disabilities, and in particular those with high support needs. The issues of inclusivity in research are an aspect of my overall theme of the tension between inclusion and difference. I consider whether there are specific barriers to engaging people with learning disabilities in research, and to what extent research in Learning Disability has been inclusive and has challenged the causes of disablement for people with learning disabilities. To address these questions I engage with debates about research ethics and praxis posed by social model of disability theorists.

Section 2 considers the early studies on people with learning disabilities which first tried to consider their perspectives but were then heavily influenced by deviance theory. I include this earlier work because I think it is important to emphasise that challenging the exclusionary impact of research is not merely a question of overcoming limitations of method, but as social model theorists argue, may also require analysis of the theoretical positioning of the researcher. Whilst acknowledging the problematic assumptions of this research, I point out that sociocultural dimensions cannot be dismissed in accounting for the disabling barriers experienced by people with learning disabilities.

Section 3 considers the development of research with people with learning disabilities, and reviews the debates about how such research should and can be conducted, with particular reference to the social model of disability and the distinction that has been drawn between participatory and emancipatory research. I begin by identifying some of the central debates in disability research with people with learning disabilities, including the empowerment or

disempowerment of research subjects and whether research reinforces or can challenge oppressive power relationships. These debates are not unique to research with people with learning disabilities, but I review how these issues have been tackled in learning disability research, and the strategies that have been applied to attempt to overcome any exclusionary impact of research.

Section 4 examines the challenge of doing research where there are specific exclusionary barriers, including, issues of access (for both researchers and the researched), methodological limitations, in particular the reliance on word and text in understanding the social world of people who do not communicate in words, and beliefs that research with people with severe or profound cognitive impairment cannot benefit others. I argue that to be fully inclusive researchers need to develop strategies to tackle these barriers and that people with high support needs should not be excluded from taking part in research, even if few of the principles of emancipatory research can be upheld. Attempts to restrict research on the grounds either of protection or of participation will further delay the development of standards for ethical and sensitive practice, as well as restricting evidence of why policies and services need to change.

2. Sociocultural perspectives and disablement in the study of people with learning disabilities

Early studies that sought to investigate the perspectives of people with learning disabilities illustrate how theoretical preoccupations are as significant as limitations of method in leading to particular representations of people with learning disabilities in research.

The studies led by Edgerton from the 1960s were the first to attempt to provide an account of the experiences of people with learning disabilities in a way that included their perspectives. Prior to the 1960s, research with people with learning disabilities was mainly conducted by psychologists who tended not to make their normative assumptions explicit in their work (Manio and Bersani, 1987 cited in Gerber, 1990). From the 1960s, 'new humanistic perspectives'

(Gerber, 1990:10) were introduced by researchers who sought to describe the experiences and perspectives of people with learning disabilities using ethnographic methods. In the 1960s through to the 1980s, Edgerton, now at the University of California, Los Angeles, conducted a series of studies in hospital and then community settings. He argued that Learning Disability had been unjustly neglected by sociologists for whom it was a fitting topic because it was socially and culturally defined (Edgerton, 1993b:6). In the preface to his study of people who had moved out of the Pacific State Hospital, he argued that in previously neglecting the study of incompetence (sic), sociology and anthropology were missing the possibility of important theoretical insights.

His best known work follows the life experiences of people with 'mild mental retardation' (sic) who had been discharged into the community from the Pacific State Hospital without formal support, after they had demonstrated capacity for successful employment and were living without formal support. Influenced by Goffman's (1963) work on stigma, Edgerton interpreted the respondents' accounts of their problems as due to their experiences of institutionalisation. They regarded the social barriers they faced in the community as the causes of their problems, but he saw these as evidence of 'passing', that is, denial of their impairment. He argued that the stigma of mental incompetence was so great that in order to be accepted, people had to pretend to competencies they did not possess and hide their impairments. His book, 'The Cloak of Competence', sub-titled 'stigma in the lives of the mentally retarded' was first published in 1967, and was an important influence on normalisation (Edgerton, 1993b).

Edgerton's work has been critiqued by Gerber (1990) who argues that he failed to listen and give credence to the accounts his respondents gave him of their own lives. He attributes this to Edgerton's conception of 'mental retardation' as a totalising and unalterable condition which prevented him from seeing other aspects of his respondents' lives or listening seriously to their accounts. By contrast, Bogdan and Taylor saw 'mental retardation' (sic) as socially and culturally constructed and sought to examine the subjective experiences of people who had been given this label (Gerber, 1990:10, Klotz, 2004:97). They were interested in what made for successful acceptance in the community, as in Bogdan's study of a rural community's defence of a 'simple' (sic) farmer accused

of murder (Bogdan, 1992). However Klotz (2004:98) argues that these and later sociocultural studies assume that labelling predetermines the social experiences of people with learning disabilities and fail to allow for the other social meanings that they may give to their own lives.

This earlier interactionist tradition in learning disability research has been criticised because of its association with deviance theory (Klotz, 2004). As I have shown, one consequence of the positioning of this research is that it resulted in an unwillingness to validate the perceptions of people with learning disabilities themselves. Mike Oliver in fact proposed that interactionist sociological theory and interpretative methodology formed an outdated paradigm for disability research, because they located the causes of disablement in the individual (1992:106). However the problems with the legacy of these traditions in Learning Disability research do not foreclose the question of how such research should address the discrimination which people with learning disabilities face from hostile reactions from others or the emotional impact of harassment. The task of challenging negative representations is of great significance to self advocates and researchers working alongside them and other writers have acknowledged the importance of sociocultural causes of disablement. Goodley (2004) refers to the critique of Corker (2002) that the materialist emphasis in British disability studies has marginalised impairments where the barriers may be more in the sociocultural spheres. Atkinson (2004) comments that such changes in perception are more likely as outcomes from this work than changes in material circumstances, but that they are important for people with learning disabilities precisely because the silencing of their voices has been a significant instrument of their oppression.

In this section I have explained why some of the earliest studies to consider the social worlds of people with learning disabilities are now considered to have reinforced negative reputations, and this had led to a rejection of the interactionist tradition. However, the sociocultural causes of disablement still need to be addressed in accounts of the social contexts of people with learning disabilities.

3. The social model of disability and research with people with learning disabilities

3.1. The social model and emancipatory research

Debates about the approaches and ethics of research with people with learning disabilities reflect those of the wider disability movement about the purpose and conduct of research and how it can be conducted in ways that challenge, rather than reinforce, conditions of disablement. Social model of disability theorists have exposed the power relations within disability research and called for a new paradigm of emancipatory research to challenge the role of the non-disabled researcher and the conditions of research production (Oliver, 1992, Zarb, 1992, Barnes, 1996b). They critique research that has reinforced existing power relations and failed to lead to transformative change in oppressive structures. They argue that disability research should be controlled at all stages by disabled people, should have an explicit advocacy role, and should have outcomes that contribute to overcoming the barriers experienced by disabled people. In his original distinction between 'participatory' and 'emancipatory' research, Oliver identified the commitment of researchers to challenge the causes of oppression as the key characteristic of 'emancipatory' research (1992:102). Like Barnes (2003), he did not insist that only disabled people can do disability research, but he argued for a change in the relationships between the researcher and the researched:

This does then mean that the social relations of research production do have to be fundamentally changed; researchers have to put their knowledge and skills at the disposal of their research subjects, for them to use in whatever ways they choose (Oliver, 1992:111).

Oliver proposed that in order for research to become more relevant to the lives of disabled people, the research agenda should focus on the features of the able-bodied society that marginalise disabled people, and the processes of research should enable influence by disabled people and their organisations over the research and more 'self understanding' (1992:112) by researchers. Zarb

(1992) saw the greater involvement of disabled people in research (participatory research) as a possible step on the road to emancipatory research, and considered that the greater influence disabled people's organisations had over the research process the more likely the research was to be relevant to them. Barnes (1996b:110) called for a research stance that was unequivocally committed to the goals of the disability movement. Reflecting on his experience a decade later, he considered that the best way to ensure that disability research furthered the empowerment of disabled people was to make it accountable to disabled people's organisations:

Within an emancipatory framework it is organisations controlled and run by disabled people that devise and control the research agenda and, equally importantly, to whom the research findings should be disseminated (Barnes, 2003:13).

The contention that all disability research should or can always be conducted this way has been contested by Shakespeare and others (Shakespeare, 1996, 2006, Davis, 2000, Walmsley, 2001, Danieli and Woodhams, 2005), but the principles that have been elaborated provide the reference points for the discussion that follows.

It is acknowledged that research has often been a site for reproducing the exclusion and marginalisation of people with learning disabilities (Gillman et al., 1997). However the absence (Atkinson, 2004), negative representation (Booth, 1996) and othering (Roets et al., 2006), of people with learning disabilities in research practices and accounts, has been challenged in the last twenty years by a growing body of research that seeks to engage with people with learning disabilities to represent their experiences and perspectives. Walmsley and Johnson, reflecting on twenty years' personal experience of these developments, celebrate the distance travelled from '... long-held assumptions that people with learning disabilities had nothing to say that was of value to researchers' (2003:11).

Approaches that have been developed to increase the participation of people with learning disabilities in research include life history work and people with learning disabilities acting as 'co-researchers' alongside professionals. However these approaches raise issues of power and ownership in the research

relationship, such as who has most influence in shaping the story being told. One way in which some researchers have sought to deal with this, is by positioning themselves politically as allies of the self advocacy movement of people with learning disabilities (of which People First is the best known organisation), and epistemologically as learners pursuing shared, but partial, learning which is co-produced in the relationship between the self advocates and the researcher. Increasingly self-advocacy groups and their allies are challenging the power exercised over knowledge production through the formal processes of academic research and publishing, by demonstrating new models of engagement in research and accessible forms of dissemination.

3.2. Life history work and narratives of resistance

At the Open University, a school of 'life history' work has been developed by Atkinson and Walmsley, in which historians have supported individuals to reconstruct their personal experiences ('life stories') and put these in a wider historical context. These authors would argue that their work does more than merely describe the experiences and conditions of disablement, a charge levelled against some disability research by social model theorists. Life story work has sought to challenge the incompleteness of the historical record by enabling people to tell their own stories and, it is argued, restore the memory of 'forgotten lives' (Atkinson et al., 1997, Brigham et al., 2000). Oral histories can challenge official accounts based on documentary sources, such as case records and assessments, which may largely represent disabled people as problems, and can be seen as an example of history from the perspective of the oppressor, paralleling the experience of women, children and peoples subject to colonial power.

Atkinson and Walmsley (1999) illustrate how the official narratives in case records were used to justify the admission of people with learning disabilities to institutional care following the 1913 Mental Deficiency Act. By speaking to people about their experiences, historians argue that they are helping to provide a different story of what happened in the institutions. Such 're-authoring' can

therefore be a way of countering the objectification and devaluing of people with learning disabilities in professional pathologising discourses, by providing alternative stories of uniqueness and individuality (Gillman et al., 1997). There is now an international body of work that analyses the experiences of people living in and leaving long-stay institutions (for example, Mitchell et al., 2006, Johnson, 1998, Johnson and Traustadodottir, 2005, Manning, 2009), which has involved not only recording personal memories, but also researching what was going on in the institutions, and the policies that framed these experiences.

Some practitioners of life history work acknowledge a quasi therapeutic strand to their work, (for example, Atkinson, 2005) which is likely to be much more controversial from a social model perspective. It is argued that by recounting and having their story represented and published, some people with learning disabilities can have their personal recollections validated (Fido and Potts, 1997), the legitimacy of their point of view affirmed, and derive recognition of the valued status of their personal histories (Atkinson, 2004). Atkinson (2004, Atkinson et al., 1997) argues that, by co-authoring their stories, some people are able to overcome the exclusion and separation they have experienced, for example in an institution, by reconnecting with a mainstream historical narrative. For example, Mabel Cooper, who was assisted by Dorothy Atkinson to tell her life story, explains that she was institutionalised because ‘people were frightened of us’ (Atkinson et al., 1997:111). She became Chair of a People First Group and now gives talks to children in schools to try and change such attitudes. Life story can be seen as one way of seeking to overcome the exclusions that have been faced by people who were institutionalised, and whose experience includes, not only being physically shut away, but also being denied access to information about their own histories.

The use of new digital media is now being used to extend the life history approach. Manning (2009) has used digital storytelling with former residents of Kew Cottages in Australia. In addition to participants being able to check and then keep their stories on CD, dissemination of life histories through DVD and the web has made them available to a wider audience.

Accounts of exclusion and abuse have been counterpoised by alternative narratives of resistance. Goodley (2005) has identified the resilience of self advocates who survived oppressive lives and practices, both in institutions and in the community. In reconstructing the life world of a self advocate using an ethnographic approach, Goodley seeks to recreate the life story and symbols of a self advocate and acknowledges the empowering story of his subject as 'extraordinarily ordinary' - an ordinary person living in extraordinary circumstances (Goodley et al., 2004:150). For Goodley, the sources of empowerment are the self advocates themselves, rather than the research process, and he challenges the idea of 'empowering' research, pointing out that it assumes that people are not empowered already. Historians have discovered songs of resistance remembered by some former residents of long-stay institutions, which show how some people subverted the authority of the regimes to which they were subjected (Ledger and Shufflebottom, 2006). Such songs have been recorded by Nigel Ingham at reminiscence groups of former residents of the Royal Albert Hospital, Lancaster. Stanley Byres, for example, recorded a song that he remembered singing at the annual Silverdale scout camp while on a ward known as the Barlow Home during the 1960s - 1980s:

Come to Barlow
Come to Barlow
We will find it very nice
If it wasn't for the nurses
We would live in paradise.

Build a bonfire
Build a bonfire
Put the nurses on the top
Put the charge hands in the middle
And we'll burn the bloomin' lot!
(Royal Albert Hospital Archive, 2006).

However the contention that research recovers 'lost voices' (Atkinson and Walmsley, 1999) is not unproblematic. There is no one voice that can represent the many different experiences and views of people with learning disabilities. Nor is speaking up necessarily to be equated with having power to make choices

and decisions. For example, Apsis (2000) has challenged the ownership of life history work, an issue acknowledged by Atkinson (Atkinson, 2004). Walmsley herself (Walmsley, 2001) has pointed out that some research with people with learning disabilities absorbed the 'normalisation' paradigm, seeking to emphasise the ordinariness of people with learning disabilities and eliding some differences. McClimens (2002) acknowledges the issues of authorial voice and the dangers of misappropriating biographies, but feels that there is still value in narrative affirmation of identities and possibilities for continuing renegotiation of these identities by the participants. Being silenced has been a powerful form of oppression and therefore reclaiming the power to speak for themselves, as against having others speak for them, has been a strong demand of the self advocacy movement.

Researchers have grappled with how to convey with authenticity what people with learning disabilities have had to say to them. In pioneering work with parents with learning disabilities, Booth (1996) considered that there was more meaning to the accounts of his respondents than was always conveyed in the transcription of their words. He stressed the importance of allowing time for the respondents' story to emerge and 'listening to the silences', and he advocated filling in the gaps in their narratives. He suggests that it might be more authentic sometimes to fictionalise to convey the truth of someone's message, than to produce a fragmentary narrative that does no favours to the person. Ten years later Roets (2004), acting as a supporter for the All for One Group, takes a different view. She is not in apologetic mode about the words of her co-author, and the written text of the self advocate is included in their joint article, unaltered, as an 'ethical choice':

In Dutch too, Danny's own style and language are not all the time fluid but we deliberately wish to value his choice of words and sentence structure. Our main reason makes his rebellious nature to be rather recalcitrant critical when allies change his words and texts and assail his actions too much. We would further like to ask the reader to not get irritated by grammatical and syntactical bias due to our translation as allies - from Dutch into English (Roets et al., 2004:55).

Roets accepts the self advocates' language as social action in its own right. The 'Our New Future' Group of self advocates (called 'Muskateers') stress that

they are the teachers from whom the research supporters (called ‘Tinker Ladies’) need to learn:

I the Head Muskateer and my colleagues feel the Muskateers have more power of reason to consider things within our lives than a bunch of uneducated Tinker Ladies - all together within Our New Future. *Tinker Ladies need a very decent education by us the Musketeers* because they have little or no wits of our business within Our New Future (Van de Perre and Roets, 2003 cited in, Roets et al., 2004:54-5).

Bjornsdottir and Svendsdottir research and write together as doctoral student and self advocate, and so seek to challenge the rules of the academic game (2008). McClimens, in a self-styled minority report from the battlefield of attempting collaborative writing, notes that higher education needs to be opened up for people with the label of learning disabilities to have more influence on knowledge construction. Language is at the heart of the way power is exercised through writing, or as Darren says: ‘Not having the words makes things difficult. It’s hard because the words are bigger’ (McClimens, 2008:274).

I have given examples from life stories and ethnographic research that has been developed with people with learning disabilities, in order to illustrate some of the different ways in which researchers who are committed to revealing the experiences and perceptions of people with learning disabilities have framed the purpose of their work and the ethics of their relationships with people with learning disabilities. I have suggested that the life history school has addressed issues of disablement which are significant for people with learning disabilities, that is, exclusion from both knowing about and speaking about the powerful regimes that dictated some lives. However I am persuaded by Goodley’s caution that it is a mistake to underestimate the strength and resilience of people who have survived difficult lives, and may not need research to empower them.

Language gives rise to important ethical and methodological issues which highlight the power dynamics in Learning Disability research. Goodley, like Booth before him, seeks to convey the meaning of a person’s experiences and does not exclude adding to their words to convey his sense of the person and their life, whereas Roets in part reproduces the language of the self advocates, however unconventional. Both seek to develop a narrative in which the person’s

individuality is expressed and their circumstances analysed without portraying them as victims. Others challenge the difficult language in which research is expressed and seek to open up research knowledge and expression to people with learning disabilities.

In the next section I consider the conditions of research production and how these can present barriers for people with learning disabilities. Debate has been joined in the literature about the role of the research supporter, the power of the researcher/author/interpreter and the place of emancipatory research with people with learning disabilities. These debates open up a space in which to theorise the interaction of the researched and researcher and to extend disability theory as applied to research to people with learning disabilities; I believe that these debates are significant for social research in general.

3.3. The conditions of research production

The social model of disability illuminates the oppressive structures and relations which exclude people with learning disabilities in and through research. The systematic, discriminatory impact of the dominant conditions of research production has limited the possibilities for greater influence upon research by people with learning disabilities in particular ways. For example Goodley and Moore (2000) reflect upon the dilemmas of seeking to reconcile alignment with the self advocacy movement and academic legitimacy, describing how the parameters of their funded research restricted their participatory intent, and how formal expectations of research dissemination marginalise accessible approaches. Inaccessible information is a major barrier to control by people with learning disabilities and their involvement in developing alternatives is critical to counter disempowerment (Ward and Townsley, 2005). Thus there are barriers to the engagement of people with learning disabilities in the research process.

What has been described as an 'inclusive' research approach seeks to maximise the participation of people with learning disabilities in research (Walmsley, 2001, Walmsley and Johnson, 2003). Co-research and co-writing have emerged

as ways to support people with learning disabilities to be active research subjects. 'Support' may consist in asking questions to prompt the account, recording and transcribing of the story, organising it, feeding it back to the author for comment and securing publication. It may also involve work to make the research process itself more accessible. For example, Williams, who has worked as a supporter to co-researchers working as self advocates, has also sought to make research findings accessible and meaningful to people with learning disabilities through the 'Plain Facts' series (Williams, 1999). Research training, developing accessible information together and jointly choosing the research topic, are ways in which power imbalances can be reduced and research made more useful to people with learning disabilities themselves (Ward and Simons, 1998, Williams and Simons, 2005, Johnson, 2009).

An issue that is raised by co-research and co-writing is the power of the research supporter in co-research practices. Where support is provided to co-create a life story account, for example, the power of the researcher/facilitator in structuring and interpreting the story is considerable. Walmsley (2004) argues that obscuring the role of the research supporter/interpreter makes it harder to see how the research has been done. She points out that her colleague Dorothy Atkinson chose not to include her name in Mabel Cooper's story which she had helped to produce, and she calls for much greater transparency in the role of the listener/supporter, not least so that new researchers can be trained to act effectively in this facilitating role. She proposes a contractual basis for co-researching to make the research relationships clearer (Walmsley and Johnson, 2003). The individual or the self-advocacy groups may have a different agenda from the researchers (McClimens, 2008), and Johnson explored the tensions of working inclusively in the 'No Longer Researching About Us Without Us' project in Ireland, where the available support was through service providers, rather than advocates (Johnson, 2009). The social context will therefore also affect the possibilities for inclusion.

A challenge posed by the social model of disability is who should be doing disability research. Some self advocates and their allies have argued that the active construction of people with learning disabilities as research subjects, without power or control over the process or products of research, has

reproduced their disempowerment, and that therefore they should conduct their own research. The Carlisle People First Research Group is a relatively rare (published) example of people with learning disabilities doing their own research (Townson et al., 2004). They divide research into 'person led research', 'which is started and controlled by people who have learning difficulties', and what they term 'rejected research', when they are not part of research which is about them or not completely included (2004:73). The Group argue that they are best placed to do research about the lives of people with learning disabilities, and that if others do it this reproduces the exclusion they have experienced throughout their lives:

Many people have been rejected in their lives and rejected at school. We have been rejected from society, and should not be rejected from research especially when it is about us. People who are not in the same boat as us don't understand what it is like to be us, they have not had our experiences (Townson et al., 2004:73).

However some researchers have voiced concerns that 'nothing about us without us' may restrict the development of research with people with learning disabilities by rendering off-limits aspects of the research process that are harder to make accessible. Walmsley has noted (Walmsley and Johnson, 2003) that some academics collaborating with people with learning disabilities feel able to publish complex papers on methods, but can be reluctant to analyse content in ways that are not accessible. Goodley (2005) has restated the importance of finding a space in which theory and praxis can be debated in order to advance the interests of people with learning disabilities. Other writers (Riddell et al., 1998, Stalker, 1998, Walmsley, 2001) have expressed the concern that there is a risk of exaggerating the role taken by participants with learning disabilities in order to represent them positively and stress their active agency. This may actually obscure the changes needed to the conditions of research production for people with learning disabilities to be active participants in research.

Self advocacy groups, with support, have been finding out what they want and need to know to take part in research (Abell et al., 2007, Ham et al., 2004). Alongside their efforts, the capacity of researchers and research centres to work in different ways also gets developed (Ward and Simons, 1998, Williams, 1999, Williams and Simons, 2005). Working collaboratively and inclusively takes time

and also requires a commitment to do things differently and challenge academic conventions. The changes to research practice which these authors identify as required include: acceptance of the validity of using a wider range of methods to access people's perceptions and lived experiences, and of the possibility that approaches may vary according to the different communication requirements of individuals; different training for researchers so that they can act in supportive and facilitative roles; time within funded research to build a relationship with participants over an extended period, and for information to be provided in multiple sessions; opportunities for research participants to gain skills, learn from other information and share experiences with other participants; and, greater legitimacy for alternative and accessible methods of presenting and disseminating research results and recommendations (Goodley and Moore, 2000, Gilbert, 2004). Stalker (1998) identified the need for training for people with learning disabilities to use their expertise in research advisory groups. Garbutt (2009) reviews the criteria for academic publishing and discusses the tensions in attempting to transform publishing practice and reconcile academic and accessibility standards, which she has published in 'Change', an accessible research report (Garbutt et al., 2009). These are potentially transformative changes as they require a shift in the focus of resources from obtaining data to enabling people to be active research participants. The requirements for additional time and resources are greater when it is the intention to train people with learning disabilities to be co-researchers. The justification for these therefore has to be clear, or they will be seen as an unacceptable burden in competing for research funding.

Strategies to engage people with learning disabilities more fully in research do not by themselves necessarily lead to a greater equalisation of power in the research relationship itself, or to a challenge to the causes of disablement. There are issues of power and ownership in the practice of co-research, and these should be debated and theorised amongst researchers and people with learning disabilities, so that the ethics and methods of research practice can be developed to take account of these. However the exchange of skills and experience that is called for by the encounter between people with learning disabilities and academic research can be generative for theory and method. Some researchers, while recognising that people with learning disabilities have

not controlled the research they have done, have sought to find ways to develop a research practice that furthers the interests of disabled people, and allows for a sharing of knowledge as part of a shared struggle for social change.

Goodley theorises his position in acting as an ethnographic researcher on self advocacy and a volunteer supporter to a self advocacy group (Goodley, 1999). He seeks to avoid privileging the 'knowing' of the non disabled researcher by learning from the disabled people who are experts on their own lives and means of liberation. Goodley also brings his own subjectivity into the analysis in order to provide a reflexive account of his position and his relationship with the self advocates. Roets positions herself as an ally of the self advocate Goedgeluck, and together they write as joint 'subjects in dialogue' and engage in 'shared discovery' in life story work taking a postmodernist, feminist approach (Roets and Goedgeluck, 2007:85). Their knowledge emerges out of their everyday exchanges: 'In our experience, our knowledge is gained, in particular, in informal space created between us' (2007:93).

Both Roets and Goodley propose developing a critical dialogue which grows out of the social relationships that they have with the self advocates they know. They make their values explicit and align themselves as social activists with the goals of the self advocacy movement. This perspective is of course not confined to disability studies. Knowing, as the product of interpersonal relations, is a feature of feminist research (Humphrey, 2007). It is a strategy that has the potential to challenge the 'othering' inherent in the ethnographic enterprise of using relationship to produce an 'insider' account. An important dimension is that the researcher endeavours to be reflexive, aware of the influences on their own positions and interpretations so that they acknowledge the limitations in their own understanding. When the researcher acknowledges their own subjectivity and also explores the connections and differences between themselves and the other, they may be able to represent more than one subject position. I feel that the capacity to represent difference without othering may be an important capability for research with people with learning disabilities.

3.4. Conclusion

I have argued in this section that the conditions of research production need to change if people with learning disabilities are to engage with research, and that the social model of disability raises key questions about the purpose, conduct and ownership of research. A support relationship is likely to be part of the conditions of effective research with people with learning disabilities, and so it is important for the development of ethical research practice to find ways to increase the mutuality of that relationship. Theorising and reflecting on the exchange of skills, experience and knowledge, which can occur in the co-production of research, connects research with people with learning disabilities with wider research debates, particularly with feminist research. Partnerships between researchers and people with learning disabilities raise issues of power and control, and there is an increasing body of work which attempts to clarify the conditions under which ethical and effective practice can take place.

In the next section of this Chapter I consider the inclusivity of Learning Disability research itself and ask who has not been included and why. I examine limiting barriers in three areas: access, method and beliefs and this leads me to address particularly the need for specific strategies to include people with non verbal communication and profound cognitive impairments.

4. Towards inclusive research

4.1. Introduction

The purpose of this section is to consider where there have been limitations to the inclusion of people with learning disabilities in research. I first review why some people are seen as more difficult to engage than others and who has been missing from Learning Disability research. I question whether in fact it is the characteristics of 'difficult' research subjects that are the problem. I consider three barriers to engaging with difference: regulations designed to limit access

to people without capacity to consent; the dominance of word-based knowing which may marginalise those who communicate in other ways; and beliefs that people with profound intellectual impairment do not make sense of their worlds and therefore have nothing to offer the development of knowledge. I argue that research competencies are extended by tackling these barriers and that policy and practice cannot be developed adequately when the research base systematically marginalises or excludes some experiences.

4.2. Absent subjects

A variety of terms have been used to designate research subjects who are likely to be marginal in research studies or only included with extra effort. In social care research, terms include 'hard to reach' and more recently 'vulnerable people'. Such terms locate the problem with the marginalised group, rather than examining the processes which distance them from the research enterprise. Examples of people often under- represented in research with people with learning disabilities tell us something about the label of learning disabilities.

The particular way in which the label of 'learning disability' has been constructed, with historical definitions based on specific measure of intellectual (in)capacity (see Chapter One) has also obscured other differences which have been subsumed by the label of 'learning disability', most obviously people on the autism spectrum, not all of whom have intellectual impairment. Waltz uses a cultural studies approach to examine how the writers of medical case studies which shaped the 'dominant discourse of autism' (Waltz, 2005:423), portrayed their subjects as 'other' and not as individuals, so emphasising their own power and competence. He contrasts these with the personal narratives of individuals and parents which describe their lived experience and challenge assumptions about normality. Williams provided some of the first 'insider accounts' of living with autism (1992, 1996). Billington (2006) argues that a social deficit model of autism has prevented professionals from examining the social contexts in which people on the autistic spectrum develop their feelings, thinking and sense of meaning. He suggests that there would be much to learn from autism research about the different ways that people experience and make sense of their worlds,

but that this would be threatening to many professionals because it would challenge the way they understand their own consciousness. The consequent 'crisis of meaning' is a barrier to trying to understand people with autism on their own terms: 'When we meet an autistic child, therefore, we may not merely be confronted by their deficits or impairments but by our own' (Billington, 2006:11).

Thus Billington suggests that the differences in the way people with autism perceive their worlds provide a challenge to neurotypical understandings which, if ignored in research, closes off the development of knowledge which would be of wider benefit.

People on the boundary of the classification of learning difficulty create a problem for research based on such categorisation. Since the threshold for the definition of impairment along the spectrum of intellectual capacity is arbitrary, people with mild impairment who may manage without services, but may sometimes have difficulty in managing some aspects of their daily lives without support, will only enter the purview of research and services when there is a problem. Simons (Simons, 2000) described the ups and downs of people living 'on the edge'. More recently there has been a focus on people with 'borderline' learning difficulty who are in prison (Talbot, 2007), but whose needs may have been missed by a stricter definition of 'learning disability'. People with the label of challenging behaviour are more likely to be included in research that considers the management of their behaviour than in other social research. An exception is the work of Johnson, who spent more than 20 months as a participant observer in a locked unit of a Melbourne Hospital alongside 21 women who had been labelled with learning disabilities and challenging behaviours (Johnson, 1998). She construes some of their behaviours as individual acts of resistance in an oppressive environment.

An impairment-based categorisation overshadows other dimensions of experience and therefore may homogenise people with the label of learning difficulty, omit important differences, and predetermine explanations of these differences. Researchers have begun to explore other aspects of the social identities of people with learning disabilities such as gender and age. McCarthy has described the gendered power relations in the lives of women with learning

disabilities (McCarthy, 1998), while Williams and Nind point to the normative assumptions of sex education for women with learning disabilities (1999), and Scior (2003) identifies the contradictions that women with learning disabilities experience in trying to position themselves in relation to the dominant discourse of disability and gender. The experience of women has also been researched through life histories (Atkinson et al., 2000). Hamilton (2009) reports life histories from older women in Ireland which include their accounts of confinement, and their positive memories, and draw lessons for service providers.

In this section I have questioned the label of learning disabilities as a determining characteristic, and have pointed out some dimensions of experience that have not been represented in research with people with learning disabilities. In the rest of this Chapter I explore the barriers to research that particularly affect people with more severe or profound impairment, and I will argue that it is to the limitations of research, rather than to limitations of the person, that we need to pay attention. I turn first to the difficulties in access that arise in research with people deemed not to have the capacity to consent. In later sections I shall deal with the privileging of words, which may deter research with people who communicate in other ways, and finally, with beliefs that research with people with profound impairment is without general value.

4.3. Access to research with adults with incapacity

Research governance is an area in which the tension between participation and power is evident. New legislation in Scotland makes provision for proxy decision-making on behalf of people for whom incapacity has been established. While putting in place safeguards to protect their interests, it also imposes conditions that restrict research and suggest that the only legitimate research is research that will directly benefit them or people with similar impairments. There is parallel legislation in England and Wales. Concerns have been voiced that a restrictive approach to consent and confidentiality procedures may delay and put at risk research participation, for example with children with learning

disabilities (Scott et al., 2006) or men with learning disabilities at risk of sexual offending (Hays et al., 2003). The legislative direction has some tensions with developing practice in which processes of ongoing consent and feedback are seen as most meaningful (Cameron and Murphy, 2006).

The Adults with Incapacity (Scotland) Act 2000 brought to fruition work begun by the Scottish Law Commission some years before, to identify a legal framework for interventions with adults (defined as aged 16 and over) who are unable to make decisions for themselves (Scottish Law Commission, 1995). Therefore it includes people with cognitive impairment for whatever reason, including learning disability, dementia or brain injury. Consent to research is dealt with in Part 5 of the Act, the part of the legislation which covers medical treatment. A subsequent Code of Practice issued in 2002 and revised in March 2008 (Scottish Executive, 2008), explains how the provisions should be implemented. A Code of Practice does not have legal force but may have legal implications if not followed. The Act allows for research with adults who cannot give consent to be authorised under certain conditions. The overriding principle is that similar research could not be conducted on adults that could give consent. Other conditions are: that the research must either be of direct benefit to the individual or, exceptionally, benefit others with similar impairments; that the person themselves does not indicate an unwillingness to participate; that the research involves little or no risk or discomfort; that consent has been obtained from a person with relevant powers (for example a guardian or welfare attorney with powers to consent to research participation or the adult's nearest relative), and that the research has been approved by the Ethics Committee.

The fact that consent to research is dealt with in the context of medical interventions may account for the restrictive approach to 'benefit' justified under the legislation. The Act discourages research that could be conducted on other populations and defines the legitimate benefit from research as follows:

This is where the research is likely to improve the scientific understanding of the adult's condition and in the long term can contribute to the attainment of real and direct benefit to persons suffering from the same incapacity (Scottish Executive, 2008).

The position in England and Wales is similar. The Mental Capacity Act (2005) sets out conditions for the conduct of 'intrusive research'. To be lawful research must either:

- have some chance of benefiting the person, in which case the risk must be proportionate or
- the purpose must be to provide knowledge about the cause or treatment or care of people with the same impairing condition or a similar condition.

The research provisions of the English legislation start with a strong statement about the importance of research and their Code of Practice allows for quite a wide interpretation of benefit. Benefit to the person could be indirect such as influencing a policy that might affect them. Benefit for people of the same or similar conditions could be, for example, the impact of an aspect of daily life for people with the 'condition', but with the same restriction that it must concern the wellbeing of people with the same or similar impairment remains.

In this section I have suggested that the legal boundary drawn between adults deemed to be with and without capacity has problematic aspects when determining codes of practice for research. The notion of informed consent to research is bound up with definitions of intellectual competence. Whereas it is essential that there are ethical principles and safeguards to protect people from harm by research, the principle that research with people deemed to lack capacity will only benefit those with similar impairments seems to ignore the benefits that their experiences could offer to others in society. It is a concern that the restriction of research to studies that can only be carried out on this population may discourage researchers in other fields from considering whether the situations of people without capacity may be illuminating for their work. I would argue that studies considering health needs, housing, transport issues, the experiences of younger or older people should include the experiences of people covered by the Act.

In the next section I consider how a lack of formal communication can be a barrier to research participation, but argue that it is the communicative competence of researchers that should be interrogated and extended.

4.4. Alternative communication

People who do not communicate using words or who have expressive language difficulties, present a particular challenge to social research because of the privileged nature of speech and the written word in qualitative discourses. The stereotypical image of the research informant is of a person who can engage with an interview, and formal traditions of research dissemination also depend on engagement with the spoken and written word.

In the early 1970s Goode began pioneering work that challenged the assumptions that absence of speech equated with lack of meaningful communication, and that lack of formal communication rendered impossible the exploration of a person's social world. A student of Garfinkel, Goode carried out ethnomethodological work with two deaf blind children, Christina and Bianca, who had been affected by Rubella (Goode, 1994). By exploring and interacting with them he showed that their communication was meaningful despite their absence of speech. Goode's exploration of their communicative worlds took place over a three year period, and his work illustrates how a researcher may need to try out a whole range of approaches if they wish to engage with someone who does not employ formal means of communication.

Subsequently Hewett and Nind (1998) developed an approach they have called Intensive Interaction for working with people who use pre-verbal techniques, such as facial expressions or body movements, to communicate. Leaning and Watson (2006) show that with such support, people with profound impairment could learn new skills in social interaction. Thurman and colleagues point out that where someone does not use formal means of communication such as writing, speech, signs or symbols, the responsibility for successful communication must lie much more on the person communicating with them, who has to try to identify and match their personal, informal communicative signals (Thurman et al., 2005:85).

Communication with people who do not use formal communication systems therefore is possible, but is intensive and takes time. In a two year drama project at Sunfield School in Worcestershire, with the support of speech and language therapists, six young people with profound and complex learning needs were involved with pupils from a mainstream school and their views were elicited by the communication approach appropriate to each individual. The writer comments that it is an obligation to find ways to take their views into account (Whitehurst, 2007). Grove and colleagues (1999) and Ware (2004) discuss the issues in obtaining and interpreting the communication of people with profound impairments; over time it may be possible to interpret preferences and some meanings, but this is not the same as obtaining 'views'.

Technology can assist communication by some people who do not use words or have limited speech. Techniques of alternative and augmentative communication have been developed to make it easier for people to communicate preferences. For example the technique of Talking Mats can enable people to indicate a choice by pointing or blinking. It can prolong an interaction and so increase the possibilities of communication, and has been found to be effective in improving on the main communication method of people with learning disabilities who understand three or more information carrying words per sentence (Murphy and Cameron, 2008). Brewster (2004) used peer informants to select the vocabulary to be used with Talking Mats. The Rix Centre has been working collaboratively to explore the potential of multi-media and the web to contribute to inclusive communication (Bunning et al., 2009).

It may be appropriate for researchers to focus more on their own lack of communicative competence, than on the failure of their respondents to use the same communication systems as themselves. The Booths (1996) showed how research methods that assume verbal fluency and other characteristics of the informed subject, conspire to silence the experiences and stories of those who convey their meaning differently. They conclude that 'researchers should attend more to their own deficiencies than to the limitations of their informants' (Booth and Booth, 1996:56). The practices of qualitative research, such as the use of open questions, may actively disempower research participants who require support to speak or maintain boundaries (Swain et al.,

1998, Owens, 2007). Lloyd, Gatherer and Kalsy (2006) argue that qualitative researchers should and can adapt their methods to overcome the difficulties of listening to people with expressive language difficulties. There are parallels in the development of research with people with dementia where researchers may have to respond to loss of memory, communicative, and cognitive capacities. Heather Wilkinson's work with people with dementia has shown that researchers can support some people with dementia to contribute memories and opinions (2002) and McKillop, a man with early onset dementia, has published advice to research interviewers (McKillop and Wilkinson, 2004).

The opportunity to build a relationship over time may be as important as finding a particular communication tool (Klotz, 2006). However Davis (1998), reflecting on research into the social worlds of children, cautions that immersion in a culture or setting is not the same as understanding. He argues for reflexivity, where the researcher is open to learning about themselves, so that the interaction between their culture and that of the people whose lives and social contexts they study becomes a source of data. In fact the 'problem' of communicating with non-verbal research respondents can be reframed as the familiar ethnographic issue of interpreting between cultures. It is through critical self-awareness that the researcher can attempt to engage with other social realities (Davies, 1998). Goodley explores this theme and writes of how he uses his own subjectivity reflexively in understanding the social worlds of people with learning disabilities. His starting-point is that as a 'nondisabled, White, male middle-class researcher' (1999:28) he does not share experiences of exclusion with people with learning disabilities. So his strategy is to be aware of his own positioning throughout the research and to see learning as a process. "Knowing" refers to an ongoing project of building a researcher subjectivity that learns from the experiences of people in the field under investigation' (Goodley, 1999:29). Such an approach recognises that knowledge can only be partial and that communication, when its purpose is to understand something of the experience of another, involves reciprocity, a negotiation between understandings, and, as social model theorists have emphasised, cannot be value-free.

A key methodological problem is how to retain the power and integrity of the experiences of a person who may not use written or verbal language, into written representations of those experiences. Goodley (1999) has called for a critical approach to life history work because of the greater risk that the researcher's preoccupations may dominate when they attempt to construct narratives about people who use words less fluently than they do themselves. The domination of the written text may also obscure the subtle expressions of agency and resistance expressed by people who do not use words or words alone to express themselves. Some researchers have explored the use of different media such as pictures, drama or dance in research dissemination, pursuing various aims, including recreating the immediacy of the research encounter, providing an opportunity for the audience to experience the material affectively, and opening up possibilities for the emergence of new shared meanings. For example, it is argued that the addition of pictures and photographs to a research report does more than remove and explain complex language, but may also increase the power of the message and draw the reader/viewer into dialogue that creates new, shared meanings (Roets et al., 2004, Roets and Goedgeluck, 2007).

Goodley and Moore (2000) comment on the success of a dramatic performance of their findings by people with learning disabilities. Walmsley and Johnson also recommend drama as a dissemination medium (2003:175). By experimenting with representing research findings in dance, Bagley and Cancienne (2001) felt that they opened up a space to convey and evoke emotion and may, therefore, have increased the possibility of social action. Ethnoperformance or ethnodrama is the translation of ethnographic findings into live performance (Denzin, 2003). This was the medium used by Kontos to disseminate the findings of her study of expressions of personhood in Alzheimer's, because she considered it particularly appropriate for revealing the embodied selfhood of persons with cognitive impairment that was difficult to convey through the written text; she also argues for the value of drama to evoke 'the experiential immediacy of the body present in the original data-gathering setting' (2006:301). Performances then may help to recreate the experience of the research subjects in engaging with the research, convey the emotion within that research experience and open up the interpretation to new audiences in order to

move them to new understanding and action. Thus performances may prevent research from obscuring the affective power of the strength of some people with learning disabilities to resist, survive and transform oppression, a power that should be available to inspire other groups, in the way that the traditions of other liberation struggles have moved others across time and space.

I have argued that researchers should extend their own communicative competence to engage with people who communicate differently and that, rather than being a very specialised research problem, this should be seen as an aspect of the wider problem of communicating between cultures. Such a perspective calls for a reflexive approach to examine the limitations and misinterpretations that may arise from the researcher's own culture, in this case a preoccupation with language as the means of interpreting the world. In the next and final section of this Chapter I consider the logical outcome of such a bias, that people with profound learning disabilities do not make sense of their worlds and therefore have nothing to offer to the development of knowledge.

4.5. Beliefs that restrict the perceived value of research with people with profound impairment

Methodological barriers seem to be only part of the explanation for why disability research with people with profound impairment has been limited. In this section I will describe how assumptions that people with profound cognitive impairment are incapable of emotion, social relationships and meaningful communication, have contributed to their exclusion from research that examines people's perceptions and their social worlds. Questioning of their status as human beings has reinforced a view that their experiences are of limited interest for understanding human society. I argue that there is a need to continue to develop specific research strategies to explore the life worlds of people with profound impairment. In conclusion, I will ask to what extent a narrow interpretation of the conditions for emancipatory research may reinforce the exclusion of people with profound intellectual impairment from research.

Social relationships, sense-making and meaningful communication are among the attributes that have been denied people with profound intellectual impairment. Edgerton's early studies of relationships between people in a large hospital in the 1960s did include an account of a friendship between people with profound impairment (MacAndrew and Edgerton, 1966). However, reviewing the development of sociocultural studies in this field, Klotz notes that whilst MacAndrew and Edgerton admitted that profound cognitive impairment might not be a barrier to friendship and emotion, they later claimed that people with profound impairment were incapable of meaningful communication and were less than human (Klotz, 2004:94). Their later work on people who had been deinstitutionalised focused on people with mild cognitive impairment. As Klotz (2004) points out, whilst Edgerton affirmed that 'mild mental retardation (sic) is a social phenomenon through and through' (Edgerton, 1993b:5), he saw profound impairment as organic, and did not believe people with profound impairment had the capacity for meaningful communication.

A contrary perspective has been put forward by researchers, practitioners and family members who have sought to understand the individuality of people with profound impairment, and to explore the social value accorded to them by others. In a 1989 paper Bogdan and Taylor explored the attributions that led to acceptance and inclusion rather than rejection and looked at how nondisabled people who were in caring and accepting relationships with 'severely disabled people' maintained a positive image of them. They found that family members continued to respect the disabled person as a valued human being by attributing thinking to them, seeing their individuality, viewing them as reciprocating and defining a social role for them. They refute the characterisation of people with profound impairment as a category:

We argue in this paper that the definition of a person is to be found in the relationship between the definer and the defined, not determined either by personal characteristics or the abstract meanings attached to the group of which the person is a part (Bogdan and Taylor, 1989:136).

In fact it is through focusing on what happens in relationships between a person with profound impairment and others that some researchers are beginning to adapt other research approaches to develop accounts of the life worlds of people with profound impairment. For example, Hewitt has conducted life story

work to provide greater knowledge of the social context in which individuals' lives may have developed (Hewitt, 2000). She has examined how the unique identities of five people with profound learning disabilities were created within their everyday interactions as they moved from a long-stay hospital to a community home. She used life story books to record how carers and relatives represented their identities on the basis that 'it is through these relationships that a sense of who the person is is realised' (Hewitt, 2000:92).

Other work has directly challenged the contention that people with profound impairment are incapable of meaning-making. Lack of symbolic interaction with objects has been used as a descriptor by those seeking to characterise a group of people with profound impairment (Nakken and Vlaskamp, 2007:84). Klotz (2006) challenges this supposed incapacity and analyses the communication of her own disabled family members. She argues that people with profound impairment do create symbolic meanings and that by ignoring their status as sociocultural beings and trying to normalise their behaviours, society and service systems deny their humanity. She contends that the social constructionist turn has defined out the possibility of people with profound impairment being acknowledged as producers of culture, and has prevented the study of the sense that people make of their social worlds.

Rather than examining the life world that this difference [the experience of profound impairment] gives rise to, researchers who adopt a constructionist perspective ignore the implications of differences as *both* productive of the sociocultural world and the product of it (Klotz, 2004:98).

There have been other challenges to assumptions that intellectual incapacity equates with an absence of sense-making (Grove, 2000). Nind (2006) has asked whether some patterns of 'stereotypical behaviours', where someone engages in repeated actions, may in fact be intentional, and serve purposes such as satisfying their sensory and emotional needs. Hogg (2007:79) identifies the social relatedness of people with profound impairment as an important dimension (and demonstration) of their personhood.

Research with people with profound impairment does pose specific issues of method, most particularly how to interpret their life worlds, given that the individuals themselves do not directly provide their own accounts of what their

experiences mean to them. However this is not a problem that renders such research impossible, as researchers have shown by inquiring into the communication systems of people in their own terms and exploring the relationships through which the person's individuality is realised. Whilst technology, and in particular video and other digital information techniques, have provided new ways to listen to people with profound impairment and offer them feedback, it would seem that theoretical preoccupations, as much as inadequate technique, have prevented their inclusion in research. Cognitively, socially and culturally, they have been seen as outside the scope of human intercourse, and thus research has reproduced their exclusion from the social order. Citizen advocacy, circles of support and person-centred planning are among the practice approaches to working with people with learning disabilities that have developed from work with people with more severe impairment (Sanderson et al., 1997). These approaches do not rely on the person being able to speak, write or understand, but instead use alternative approaches to exploring what has meaning and importance for them including their history, the knowledge of people who know them well and graphical media.

Given the unintentionally exclusionary effects of past research paradigms, it is important to reflect critically on the implications of the emancipatory paradigm. Too great an emphasis on intellectual control by research participants will rule out research with people with profound impairments. Many of the tenets of emancipatory research, as it has been elaborated to date, assume intellectual understanding as a precondition, with an emphasis on engagement at all stages of the research process and control over the research agenda. These conditions will always marginalise people with profound cognitive impairment. I have suggested that a research culture which is more open to different ways of communicating may be more enabling of the experiences of people for whom words and thinking are not determining of their experiences. However I think it is essential that researchers continue to try to develop the experience to do research with people who may never be able to understand the research enterprise in the same way as researchers intend it.

The distinction between research that merely describes the effects of disablement, and research that analyses the conditions that produce

disablement in order to transform them, remains independent of levels of impairment. Despite the risks of misinterpretation or over-interpretation in attempting to describe the social worlds of people with profound impairment, the difficulty for researchers posed by lack of access to how they are thinking and feeling, and the limits to how far the participants themselves can engage with the research findings, it can be argued that this should not preclude research that examines how material, social and cultural factors influence their life experiences in specific contexts, and how they could be more effectively supported. Not to do so is incompatible with the social model of disability research.

5. Conclusion

I have argued that, whilst it is necessary to have safeguards to protect against abuses of power in the research relationship, including procedures to protect the interests of those who cannot give informed consent, it is problematic to introduce other restrictions, standards and criteria because someone lacks the cognitive capacity to consent. Moreover the assumption that there is no general theoretical or social benefit to be gained by research on the experiences of people with cognitive impairment (or no benefit greater than the potential harm that could result from such 'intrusion'), is itself discriminatory and risks reducing the person to their impairment. This is not to deny that the power to interpret the experiences of others is greater when the research subject has no access to the medium in which their story is told, or the possibility of challenging the account. There should be a greater obligation on the researcher to be reflexive, consider what questions they may have failed to ask, and examine the influences that shaped their interpretation. A stance that acknowledges the inherent limitations on knowing may provide one safeguard for a developing epistemology on research with so-called vulnerable subjects. As a researcher I need help to know what I do not know, and people who experience the world differently from me may prove excellent mentors.

The principle that research should be used to overcome the barriers that disabled people face should be applicable to any research with people with learning disabilities. On the other hand, the view that the only legitimate form of research is one that puts the disabled person in control at every stage of the research process is also exclusionary. There are people who, even with assistance, will not be able to make their contribution directly to designing the research, co-researching or analysing the findings. However for me this raises the important question of how their participation can nonetheless be maximised, and how they can be influential in the research process. Until efforts are made to include in research people who may not contribute throughout the process, the capacity to do so will remain underdeveloped, and issues such as the need for communication support may continue to be regarded as barriers to participation.

By not attempting to explore the social worlds of people with profound impairment there is a risk that dimensions of difference in, for example, how people relate to each other, are lost. There is a danger of homogenising people with learning disabilities, and indeed, people in general, if ways of living that do not depend primarily on cognitive competence are not described. However there are also real consequences for people with profound impairment themselves. If people with profound impairment are assumed incapable of relationship, feeling, or a good quality of life, then there is a greater likelihood of abuse and little reason to improve services for them. It is therefore a legitimate research question to seek to understand their social worlds and what shapes them and to explore the appropriate ways of undertaking such an enquiry.

In the next two chapters I describe my own experience of research with people with high support needs. Chapter Three describes my research approach and how I tackled some of the barriers to including people with high support needs in research. Chapter Four describes how the research participants revealed themselves as active subjects, and how I learnt to unlearn some of my previous research practice.

CHAPTER THREE Access, Methods and Engagement: Research with people with high support needs

1. Introduction

This chapter explains how I conducted my research with people with learning disabilities and high support needs, and the rationale for the choices I made. Section 2 describes the aim of the research, my research questions and the overall design of the study. Section 3 explains the issues I encountered in accessing participants and obtaining consent, and situates my approach to consent in the particular time period at which the research was conducted, which was prior to the Adults with Incapacity (Scotland) Act (2000) (Scottish Parliament, 2000). Section 4 describes how I identified and selected participants for the case studies and who participated as a result of this recruitment. Section 5 describes how the research was carried out and how I addressed the issues that I encountered, in particular how I attempted to deal with issues of power and engagement, a theme I develop further in the following chapter. Section 6 explains the procedures I used to record data, how I conducted the analysis and addresses questions of validity. In Section 7 I seek to account reflexively for my position as non-disabled, university researcher in terms of the challenges set by the emergent tradition of inclusive research, before concluding in Section 8, on my learning about inclusive research for people with high support needs.

2. Aim, research questions and research design

The aim of my research is to examine the experience and meaning of social inclusion for people with learning disabilities who were deemed to have very high support needs. I had been struck by the relative lack of exchange between policy and political debates on citizenship and social inclusion on the one hand,

and on how to achieve a good life for people with learning disabilities on the other. I wanted to understand the barriers to inclusion through the perspectives and lived experiences of people with learning disabilities and I decided to focus on the experiences of people who were pushing support and service systems to the limits of their capacity. My rationale was that the experiences of those who were most at risk of exclusion from an 'ordinary life' could reveal issues that needed to be changed in the service system as a whole. The original working title of the study, 'Citizens: the limits to community care', reflected a concern that the intention of policy to enable people to access their rights as citizens might be challenging the scope and capacity of community services. Developments towards inclusivity in research and service systems might be leaving some people behind, despite an increasing emphasis on rights as a justification for better services (Ward, 1995). Underlying the study therefore was a concern with social justice.

My first research question was how people with high support needs were experiencing inclusion and exclusion in their daily lives. This was to be addressed by an examination of the social worlds of people with high support needs. The purpose of this part of the research was to explore the opportunities for, and barriers to, inclusion as they experienced them, and I approached the work from a broadly phenomenological stance, asking how the experience of inclusion and exclusion in daily life might be perceived by those living it (Moran, 2000:5). As explained in Chapter One, 'ordinary life' principles involve normative assumptions about what constitutes a good life, whereas I wanted to try and ascertain what home, community and belonging meant to the focal person and to understand inclusion as far as possible from the perspectives of people with learning disabilities, as a counterbalance to the understandings of policymakers and professionals. As Davis and Watson (2001) argue, in their study of the experiences of disabled children in special and mainstream schools, policy too often ignores the everyday experiences and perspectives of disabled children and of the adults who have to put educational policy into practice.

Elsewhere, Davis (1998) warns against homogenising the 'voices' of children, and an important issue for this study was to avoid suggesting that people with learning disabilities who had high support needs, would share a culture or have a

unified perspective. Therefore in order to examine a variety of experiences I adopted a case study design (Yin, 1994) that would enable me to study a small number of individuals, but with differing lifestyles and circumstances. Gomm, Hammersley and Foster characterise case studies as an intensive style of research in which information is gathered about a relatively large number of features in relatively small number of cases (2000:40). The Topic Guide and the approaches I used to collect data and engage with the study participants are described in more detail in section 5 of this Chapter.

My second research question was whether it was possible to include in research people with learning disabilities with no speech, profound impairment or behaviour that challenged. This was an identified gap in the literature on inclusive and emancipatory research practice (see Chapter Two). For example, Walmsley and Johnson (2003:170) note that the experiences of people with more severe impairments tend to appear, if at all, in the third person. The issues raised by this question therefore included what inclusive research might mean for people with high support needs, and whether their perspectives and experiences could be explored directly or only be accessed through the views of others. Exclusion from research could compound other forms of exclusion, if it were to mean that policies and services were developed and evaluated without engagement with people with the most severe impairments. In conducting the case studies I wished to test the limits of my own capacity, as an experienced qualitative researcher with no previous background in research with people with learning disabilities, to include in the case studies people who would challenge my usual research practices. I aimed to explore whether the appropriate research strategies would be an adaptation of established qualitative methods, such as face-to-face interviews, particularly as developed with other marginalised groups, or required different or more specialist approaches; the research itself therefore raised questions about norms and difference that paralleled those that were the substantive focus of the study.

My third research question was whether the thinking, policies and practices in community care for people with learning disabilities were creating barriers to comprehensive and inclusive services (Priestley, 1999). I wanted to locate the experiences of individuals who were receiving services, within an understanding

of the range of services available and the influences on the development of these services, including the ideas that were held by those responsible for planning them. The second part of the study was designed to examine these issues. It consisted of a telephone survey of service planners and managers with lead responsibility for the development of learning disability services across Scotland. The survey was designed to examine their thinking behind planning services for people with learning disabilities and high support needs, and the issues that might affect service development. I wanted to explore whether there was the desire, resources and capacity to develop services for people with high support needs. I decided on a Scotland-wide survey because the context for developing services and implementing policy varied across Scotland, and I chose the local authority as the unit of enquiry because social work departments had the lead responsibility for community care services. The survey was conducted at the same time as 'The same as you?' Learning Disability Review (Scottish Executive, 2000), and in each area my interviewees were largely those upon whom responsibility for the implementation of future policy would fall.

The two elements of the study were conceived as interactive, with elements from the case studies being fed into the survey interviews, and understanding from the interviews being used to interpret the case studies. I hoped that both elements would contribute to an understanding of how agency and structure contributed to the inclusion and exclusions experienced by people with high support needs. I was seeking ways to link micro and macro sites of power (Layder, 2006:2) and I expected to see the impact of service systems and the power of policy decisions constituting the opportunities available to individuals in their daily lives (Yates, 2005). However I did not assume that power would be exercised in one direction only, and hoped that a Foucauldian perspective would illuminate the ways in which the limits to inclusion, and also the opportunities to challenge them, might be constituted among the individuals, families, front-line workers and those responsible for developing services (Tremain, 2005:10).

I chose qualitative methods because I was seeking to explore, both in the case studies and the survey interviews, how my respondents experienced or viewed the issues in which I was interested. However I aimed to employ a number of

data collection methods, including observation, and the use of diaries in addition to the face-to-face and telephone interviews. The methodology for the case studies was broadly ethnographic (see section 4). I approached the telephone interviews as discourses on inclusion and service development (Fontana and Frey, 1998).

3. Ethics, access and consent

This section discusses the ethical and practical issues I encountered in gaining access to participants and the consent procedures I adopted. The key ethical issue presented by this study was how to balance the rights of people to participate in research and have their perspectives included, with the need to safeguard them from intrusion, or from enforced participation because they could not communicate their dissent.

I sought permission for the study from both the social work department and the ethics committee of the health trust in the area where I wished to conduct fieldwork, because I expected to need to approach both services for access to study participants. The ethics committee required a resubmission with some clarifications before giving clearance to the study. Their concern was that the research might be intrusive and their response was to clarify exactly how many visits would take place to each person and to restrict the number of these. The letter of the Committee Administrator of 18th February 1999, noted 'Section 13 [of the application] refers to 'requiring several visits to the person' and it is requested that this be more specific i.e. exactly how many visits 1, 2, 3 or 10. ... It was also the view of the committee that there were invasive procedures connected with the study in that 'three – several visits were over the norm'. They also asked that in the simplified information sheet the phrase, 'she will come to see you about three times', should be more specific.

I felt that the committee's concern that intrusion was the main ethical risk, and that an exact specification of the number of visits should be agreed, was at variance with the need to allow time for relationship-building and for attentiveness to the variety of ways that might be needed to engage with

participants. The number of visits I had proposed (three to six) was not excessive compared with similar studies. For example, Philip Seed monitored activity over two research fortnights in his follow up study of people who used day services (Seed, 1996). Moreover, I had been reluctant to specify the exact number of visits in the information sheet in case it raised expectations in anyone that they would receive the maximum possible number of visits. Misleading expectations of friendship and a continuing relationship may be considered as big a risk as too much attention from a researcher. In a four month study Stalker (1998) combined some social time with a formal research session. She acknowledges the need to negotiate both the risk of intrusion and the expectation of friendship.

I was able to convince the committee that the number of visits proposed was not excessive and that some leeway was needed because of possible cancelled appointments. I explained that, although I planned three data collection sessions, two short visits might sometimes be more acceptable than one longer one. They also accepted my explanation that there were other ways in which I would seek to avoid intrusion and respect a person's privacy, including openness, respect for confidentiality and being sensitive to the wishes of the individual. I had to agree to specify that I would conduct not more than six visits to any individual. Where more than three visits were needed, this would only be by agreement.

I expected to be scrutinised on my approach to people considered to be vulnerable, but I was less prepared for the delays in gaining access to professionals. Permission to conduct the telephone survey of service planners was obtained through the Research Training Standards Committee of the Association of Directors of Social Work (ADSW), a professional association. The study was supported by the Chair of the Learning Disability Sub-Group of ADSW, but it took a further six months to obtain clearance from the Standards Committee because of difficulties in obtaining a response, and this delayed the start of the survey.

In the previous Chapter I suggested that the restricted definition of the concept of benefit, which underlies regulations designed to protect adults deemed to lack capacity to give informed consent to research, might prevent some legitimate social research with ‘adults with incapacity’. This research was begun before the Adults with Incapacity (Scotland) Act (2000) became law and the associated Code of Practice on research was published. However the ethical issues of research with people who may not be able to give informed consent were of considerable importance for my study, and I will explain how I attempted to tackle these. There are both procedural and philosophical issues to consider in addressing the question of whether people who might not be able to understand conceptually what research is, or what it is for, should yet be able to take part in it.

Although not yet law, the Adults with Incapacity (Scotland) Act (2000) was under discussion at the start of this study. Therefore I sought advice on consent procedures before my submission to an ethics committee because I was aware of the impending Act. The advice was to seek written consent either from, or on behalf of, all participants³. This was a change of practice from the view that no one could give formal consent on the person’s behalf, as this would be a deprivation of rights, and that in the situation where the person could not give consent the researcher was bound to inform those close to them and seek approval, rather than formal consent. The consent protocol that I developed for the case studies therefore, was that I would obtain formal written consent from the person where they could give it, or else written proxy consent from someone with legal responsibility for the person, for example from their family carer.

At the time of the research there were not arrangements in place for formal assessment of capacity that could determine whether or not the person was deemed to have capacity to consent to research. I was trained to administer the Vineland Adaptive Behaviour Scale and included it in my research design, but found that it detracted from my effort to get to know the person (Sparrow et al., 2005). I explored the question of whether the person could give consent

³ Colin McKay, personal communication

with whoever was identifying the study participant, for example the day centre manager, service manager or hospital commissioner. I also ensured that others who would have an interest, most particularly family carers, received information about the study and were consulted, whether or not they were required to give formal consent or their participation in the research was required. If proxy consent was deemed to be required, I approached the appropriate person, first in writing (Appendix 6), followed by a visit to discuss the study further and seek written consent (see Appendices 7 and 8 for the information and proxy consent forms). I also prepared a simplified information sheet and consent form in large print (Appendices 9 and 11) for those individuals who were deemed able to consent themselves. The giving of information and their consent was witnessed and signed. Notwithstanding the issue of formal consent, I undertook to explain as much as possible what I was doing and why, with the assistance of others if necessary, to the person with learning disabilities. I did not view consent as a one-off process, and so I also undertook to pay attention to that person's preferences during the study and to respect their wish to withdraw at any time, whether or not expressed verbally.

In practice I was to find that the formal procedure had to be negotiated amongst several relationships. For example, I had included in my protocol that I would try to meet the person or a family carer first, before seeking any information for the study. In these preliminary sessions I would enquire about the person's stop signals and how they might indicate distress. In practice I found that it was easier to be attentive to the ethics of my relationship with the individual and their family in the study, than always to follow the letter of the protocol in terms of obtaining formal consent before any information was given. It did not feel respectful to ignore information that the family carer might be giving me in the first session, when I had intended only to provide information about the study and seek consent, as I would not wish to have to make them repeat it later. They might want to talk to me at some length at that point, as they found getting to know me the best way of finding out how I might approach their son or daughter, and they wanted to share ideas about the best way to conduct the study with them; the initial meeting therefore tended to be about mutual information-gathering, beyond the formal procedural purpose. Similarly, it was not always easy or possible to get informants who could give informed consent

themselves to wait before agreeing to take part. I therefore had to obtain agreement retrospectively before using information that people had offered before formal consent had been obtained.

A similar concern about introducing distance into the information-giving process about research has been voiced by Scott et al. (2006), who found that the requirement to obtain consent through other gatekeepers may prevent the development of a relationship in which the study can be explained and appropriate approaches developed. However it is important to note that in the case of my study, the ethics committee procedure did provide a clear framework through which to seek permission to conduct the study and scrutinize its processes.

A difference between the time at which my research took place and current practice was that then, legal responsibility for the person was not always clearly defined. The three parents who provided proxy consent on behalf of study participants with profound disabilities were clearly the people with responsibility for their wellbeing and affairs, but I do not know if their position had been legally formalised through guardianship. Similarly there were two people without the capacity to consent who did not have a relative closely involved in their care, and for them the service manager provided proxy consent. Depending on the formal legal position, it might not be possible now to have included these participants in the study. The approach of involving the person with learning disabilities as much as possible resulted in seven of the 14 participants giving consent themselves, although only in four of these cases were they the sole person providing consent. Amongst staff in services I found that there was no consensus about whether proxy consent was ethical, and most would have preferred the main effort to have been in ensuring the research was likely to be useful, and ascertaining whether the potential study participant wanted to take part.

In summary I found that, although at the time practice was changing towards a formal, legal definition of responsibility for consent, a variety of perspectives were useful in trying to determine whether the research was likely to be in the person's interest. The commitment to engage directly with the person probably

increased the proportion of respondents who were able to choose for themselves, whatever their legal status. This applied particularly to people with a dual diagnosis of learning disability and mental health problems. I felt a moral and practical obligation to involve family members who had significant responsibilities for the person, whether or not they formally held legal responsibility. I believe that this was protective for the study participant, even in one case where the relative lived on the other side of the world but was in touch by telephone and email. Finally, for a small number of people who did not have a relative involved in their daily lives, a more formal process might now be needed if they were to be involved in research, although at the time of the study there was always someone making significant decisions, such as hospital discharge, who I felt able to involve in giving consent. Cooper and colleagues have claimed that current regulations are likely to result in some exclusions (Cooper et al., 2004). Offering the choice of whether to take part in a study and engaging someone in that study is a process, and the ethical and practical issues are not resolved by a one-off decision at the beginning. The overall impact of such restriction may be that the research community does not gain capacity to work alongside people who may need active support to engage with the research process. Hammersley and Atkinson (2007:219) propose what they term 'ethical situationalism', as an alternative to formulaic regulation of research ethics. This would uphold the principles of safeguarding, but leave open the particular strategy according to the specific research context. Such an approach seems appropriate for the issues I describe.

4. Recruitment

In this section I will describe the recruitment strategy I adopted for the study and how I sought to identify informants who would reflect the range of reasons for which people with learning disabilities might be receiving a high level of support.

In order to provide a clear definition as the basis for recruitment of participants to the study, I selected the criterion that people had been assessed as requiring at least one-to-one support on a 24 hour basis. I surmised that this would mean that they were at the boundary of what community care could provide in terms of resources allocated, arrangements required and support skills demanded. Participants had to be eligible for adult learning disability services and therefore aged between 18 and 60. I aimed to recruit participants who differed according to the reason they were having a high level of support, the services they received and their personal characteristics. The term 'high support needs' had been adopted in commissioning and practice contexts as a way of shifting from a deficit-based model of disability, in which categories of people were created and admission to services regulated on the basis of a measurement of impairments (Dumbleton, 1998, Walmsley and Rolph, 2001, Race, 1995), to a more capacity-based model in which the service should respond to the level of support that the person required. It was a term that began to be used in planning documents in the study area in the mid to late 1990s, and seemed appropriate to my purposes since I wanted to identify people who posed the greatest challenge to the service system.

The participants were all receiving services in a large Scottish city. There was at that time no list of people who received learning disability services there, and so I had to find ways to identify the different groups of people receiving support, and at the same time be alert to reasons that I might be missing relevant categories of need. My strategy for finding people to take part in the study was therefore progressive, allowing for new reasons that people might have additional support as I became aware of them. I knew that some people would be known to day centres, some to area social work teams and community learning disability teams, and some to the commissioning team responsible for hospital discharge who would know about people supported by independent providers. In the first instance I approached day centres, through whom I expected to identify people living with their families, and was able, with the support of managers, to identify participants in three out of the four with which I made contact. The managers of day centres 1-3 provided profiles of people they thought would be eligible for the study. Out of 23 proposed I selected 10 on the basis that they provided a range of ages, living situation, and reason for a

high level of support. Eight were included in the study; one parent refused and I did not succeed in contacting the other family. Those selected included three people from complex needs units, and five who were not.

I also became aware, through conversations with a manager in an area team, that there were people in the community who local social work teams might consider a high priority, but who did not readily obtain funding for a service. I therefore continued to track one such situation until it became possible for me to include the person in the study. In order to reflect the development of more individualised services not based in a building, I also included one person who was no longer receiving a day service, but instead was experiencing 'day opportunities' provided by a project set up as an alternative to traditional services.

The hospital settlement commissioners provided me with a list of the 33 people discharged whom they considered to have 'high support needs', and the names of the provider agencies now supporting them. However a 'belt and braces' approach to discharge was being adopted at that point, with nearly everyone being discharged initially with 24 hour support. During the course of the study the hospital resettlement programme moved on apace and reached the final stage where a group of people were identified as the hardest to discharge, and who, in a previous phase of the resettlement, had been identified as requiring continuing institutional provision. I therefore focused the final case studies on four of these individuals in order to understand the situations that might prevent even the most basic inclusion, presence in the community. I had intended also to include three people who had already been discharged into supported living but was not able to complete these within the time (hence case study numbers 9, 10 and 14 are unused).

Thus my sampling strategy began as a case cluster approach but was then adapted because of emergent issues (Johnson, 1990). The 14 participants were then identified through day centres (8), an area social work team (2) and the hospital-based commissioning team (4). The main initial reason for a high level of support (see Table 3.1) included profound and multiple impairments, mental health needs, sensory impairment, additional health needs such as epilepsy,

challenging behaviour, posing a risk to others and vulnerability. The main reason for additional support does not comprehensively describe the varying needs among the participants, but rather may reflect the ways in which the case for funding was made within different services (see Chapter 5). For example, one of the people ascertained through the hospital discharge team also had a significant sensory impairment, but this was not seen as the main reason for the difficulty in discharging him. At least five other participants had mental health needs, and behaviour considered challenging was mentioned in another five. This emphasises the fact that people's circumstances were complex and 'high support needs', in the sense that I was using it as a measure of assessed requirement for a high level of service, was not a measure of need.

Table 3.1 Case studies: reasons for high support

Identified from	Day centre managers	Area Team	Hospital Discharge Team	Total
Main reason high level of support				
Profound & multiple impairment	3			3
Mental health needs	1			1
Sensory impairment	1			1
Health needs (epilepsy)	1	1		2
Challenging behaviour	1		2	3
Risk to others	1		1	2
Vulnerability		1	1	2
Total	8	2	4	14

As Table 3.2 shows, the services received by those recruited for the study included a mixture of traditional day services directly provided by the social work department and other models, such as day opportunities, and supported or independent living commissioned from an independent support provider. Five of the eight people attending day centres were living in the family home, but three were supported by independent providers. Of those living independently, one person was continuing to live in the family home after the death of her parents,

and one person was receiving intensive support from a provider in their own tenancy.

Table 3.2 Case studies: living situation and main services

Main Service	Day Service	Day opportunities	Support provider	Support Provider + day service	Hospital/Heal	Total
Living Situation						
Family Home	5					5
Own home		1		1		2
Supported Living			1	1		2
Group Home				1		1
Health Facility					1	1
Hospital					3	3
Total	5	1	1	3	4	14

The ages of participants ranged from early twenties to late 50s; five were men and nine were women. All were white; regrettably the family that I did not succeed in following up came from a minority ethnic background. Appendix 1 contains pen portraits of the study participants. Chapter Four provides a much more rounded introduction to the study participants and their situations.

In conclusion, I did not have the data to draw a sample that would provide a quantitative representation of the population receiving services. Rather I adopted a saturation approach, and stopped recruiting when I thought that I had included people who exemplified the different types of needs and services, as well as a diversity of age and gender. The number of case studies was less than I had originally intended because they took longer to conduct than estimated. I did succeed in identifying, through a variety of sources, people for the case studies with a range of reasons for receiving a high level of support. These corresponded to situations identified by ‘The same as you?’ as people with complex needs. However my decision to focus within the hospital discharge population on the people that had proved too difficult to discharge and were

still living in hospital, may have resulted in an under-representation of people discharged to supported living arrangements.

The recruitment process itself taught me about some of the types of circumstances that commissioners and managers of services were struggling to accommodate, and I changed my recruitment criteria to reflect my increasing awareness of the variety of reasons that people might be assessed for a high level of support. I learnt that seeking to make equivalence between intensity of support and challenge to the system was too simplistic, because I had not made sufficient allowance for people excluded from services. These experiences caused me to adjust my focus in the case studies. I focused on issues of service allocation and refusal (Chapter Five), as well as lived experiences of inclusion and exclusion (Chapter Six), and I fed these issues into the policy survey (Chapter Seven).

In the next section I describe how the research was carried out and explain the rationale and consequences of the choices I made.

5. How the research was done: choices and responses

5.1. The case studies

My research plan for the case studies envisaged a distinct purpose for each of the three planned research sessions (see Appendix 11). The first session aimed to explore ‘where and what was home’ to the study participant. The second how they spent their time and the people who were important in that person’s life. The third was intended to explore their feelings about their community, whatever that might be. Wherever possible I aimed to spend time with the person in the places that for them meant home and community and where they spent their day. In order to supplement the information I could obtain directly from the person or from being with them, I also planned to interview a family member or someone who knew the person well, to explore a typical day and to

ask them to complete a diary of the person's week. After my second meeting with the focus person, I planned to ask this other informant for examples of where they thought the person had been included in or excluded from their 'community'.

Thus at the beginning, my focus was very broad with 'inclusion' being operationalised in terms of the person's sense of belonging and connectedness at home, in their daily life and within wider networks. In order to focus the case studies, but also to link the experiences of individuals with the social processes embedded in their experiences, I came to identify an issue for a given case study in the course of the fieldwork, and I used that to determine the kind of additional work that I should pursue. Where possible, I sought to feed back my developing ideas and to test these out, whether through conversation, behaviour or structuring the case study to investigate them further. In this way the research issues became more specific, following the 'funnelling' process characterised by Hammersley and Atkinson (2007:170). I also limited the scope of my enquiries in order to minimise intrusion. I did not actively seek to know, for example, what offence the person in long-term detention had committed, or the details of someone's mental health condition. I only pursued issues that were relevant to their experiences of inclusion.

The issues that I identified for particular case studies emerged as questions during the fieldwork, as I encountered specific circumstances that were shaping an individual's experience of inclusion or exclusion. For example, when I first met Marilyn (case study 4) I found myself questioning whether I needed to know more about the effects of her impairment in order to understand whether there was any communication between us. I noticed that she appeared to respond to rhythm. Further enquiries led me to literature that indicated that young women with Rett Syndrome do respond to music which can be both a vehicle for their self expression and a medium that enables emotional engagement with others (Kerr, 1987). At this point I realised that the issue I wanted to explore with Marilyn was not in fact further knowledge of the effects of her impairment, but communication. I therefore concentrated on spending time with her and her support team. The circumstances of both Tracey (case study 7) and Michael (case study 8) raised questions for me about the relationship between need and

service provision which was to become a theme that informed the overall analysis (see Chapter Five). Despite having strong claims for support, Tracey because of her vulnerability and Michael because of profound impairment, their families had had to fight for services. I therefore went on to explore the history of their support packages and the issues that had arisen in funding these, through interviews with their social workers, service managers and their case files. An interview with Margaret's mother (case study 2) raised the issue of the continuing importance of people who had been significant in the pasts of people with complex needs. She believed that Margaret remembered her late father and I found this confirmed by support staff at the day centre. I pursued the issue of past significant relationships in other case studies and I report in Chapter Six on a striking example of the importance of past relationships that was provided by Phil (case study 15). Thus my broad themes of inclusion and belonging were particularised by issues such as communication, access to support and continuity of relationships which not only structured later stages of the fieldwork, but also provided fruitful themes for analysis.

I found that I had to be flexible in applying my study design. I did not always obtain the information I was looking for in the order that I had planned, but I used the themes of home, time, social networks and community to steer my observations and encounters and I found different ways to collect the information I wanted. For example, rather than starting with a home visit, I was only gradually admitted to Rob's private territory, as his workers felt more secure about the risks involved. I took advantage of naturalistic opportunities to spend time with someone and sometimes I encountered other relevant situations in the course of my 'sessions', for example, meeting one of my research participants or their staff when visiting someone else. Diaries were completed on behalf of two participants, but I also found out about weekly routines from support logs and interviews.

The person themselves was not necessarily in control of where they spent their time or when they went out, so I had to try and ascertain from my observations and interviews where or what 'home' or 'community' might be for them, and then to check this out in further encounters. I spent time during a weekday at

the day centre with seven of the participants, as well as spoke to staff there. I visited four of the five day centres which the participants attended. I met Mairi out and about, and saw Sheila at the hospital where she lived, also during the day time. My contact with Colin, Ruth and Ailsa was exclusively in the evenings where they were living. I went out in the evening with Rob and Marilyn, but I held back from going out in the evening with Tracey, the youngest participant and her befriender, as I was older than her mother. I paid a social visit to Stuart one Sunday afternoon and also met him at an evening advocacy event.

Table 3.3 shows the number of sessions that I actually carried out with the person: these ranged from two to six. A complete list of sessions and data items is included as Appendix 2. Overall I conducted some 61 research sessions. I soon discovered that the daily lives of people with profound impairments were complex, making the opportunities for visits limited in length and that people's health needs had a very big impact on their 'availability' for engagement with anything in their life, let alone research. For example, Jennifer, the subject of my first case study, was not at home when I visited her mother. Anne was moved to an assessment unit and although both Ruth and Colin did use words, I did not manage to communicate with them sufficiently to arrange to visit a place outside their home. I deliberately extended one of the case studies (with Tracey) in order to understand whether the restriction on visits imposed by the ethics committee was a serious limitation. The wider number of opportunities did give me a chance to see more of her life in the round and to gain a wider range of perspectives, including family and support staff. I am less sure that the impact on Tracey was wholly beneficial as she came to have expectations of a continuing relationship, for example drawing me a picture for my office wall.

Table 3.3 case study research sessions

Who (case study number)	Consent	No. Visits to person	Total Time with person	How engaged	Where	Other informants/ data
Jennifer (1)	Proxy (parent)	2	5+ hours but short time in interaction	Primarily just time with while others present, some interaction	Day centre Trip to park from day centre (only mother seen at home)	Key worker at day centre Mother
Margaret (2)	Proxy (parent)	3	5+ hours	Observations Conversations with others	Home Day centre Day centre Bus Sports centre	Mother Sister (brief) Key worker Day centre workers Sports centre worker
Anne (3)	Study participant Family also informed	2	2 hours	Interview	Day centre (brief meeting at airport) (only parents seen at home)	Mother Father Brother (brief) Weekly diary Support worker
Marilyn (4)	Proxy (service manager)	3	4-5 hours, not all in direct interaction	Interaction Spending time together	Home Visit to pub Day centre	Support workers Team leader (supported living project) Day centre workers
Ruth (5)	Proxy (Service manager)	2	3 hours	Interview (limited) Social time Listening	Home	Service Manager
Rob (6)	Proxy (Relative – not face-to-face)	3	3.5 hours	Observations Spending time A few words	Day centre Pub Home	Day centre manager Support workers

Who (case study number)	Consent	No. Visits to person	Total Time with person	How engaged	Where	Other Informants /data
Tracey (7)	Proxy (mother)	6	14 hours	Conversations Spending time Activities	Day centre Bus Home Cafe	Mother Sister (brief) Social worker Support worker Social work area manager Key Worker
Michael (8)	Proxy (mother)	4	4-5 hours	Observation only	Home Day centre	Mother Support worker Volunteer Day centre manager Social worker Assessment Day centre case file
Mairi (11)	Study participant	4	8.75 hours	Interview Time in cafe	Cafe Accident and emergency (unplanned)	Project manager Support worker Sister (brief)
Sheila (12)	Proxy (relative not face-to- face) Study participant	4	4 hours	Interview Community walk	Hospital	Ward sister Support worker Hospital manager
Stuart (13)	Study participant	5	4-5 hours	Interview	Hospital (later, advocacy project, community unit, my office)	Ward sister
Phil (15)	Study participant	3	3.75 hours	Interview with signer Writing	Hospital	Signer
Colin (16)	Study participant	2	3 hours	Interview but exchanges very limited	Home	Support workers
Ailsa (17)	Commissionin g team and study participant	4	4.5 hours	Interview Social time	Secure health facility Kitchen of support project	Nurse (brief) Support worker (brief)

Table 3.3 shows that I identified fewer other informants for the people in hospital than for the people at home, thus probably reflecting their more limited social networks. I spent most time one-to-one with three of the people who were detained patients (in one case locked in the staff room!) together with the person receiving day opportunities. Given that the entry criterion for the study had been the need for constant one-to-one support this is perhaps unsurprising. It is also noticeable that the only three people whom I managed to accompany to a mainstream community setting (two pubs and a cafe) lived either in their own house or supported living, suggesting that they had greater access to ordinary places, although in Chapter Six I write about whether their experience was indeed 'ordinary'.

When I started the study I envisaged that the core method of data collection for participants with speech would consist in a modified form of the interview, conceived by Kvale (1996) as a 'conversation', characterised by an exchange leading to the co-production of knowledge. My plans to engage the study participant included the use of photographs, to remind the person of previous sessions, and the idea that we might use drawings to describe important places and people. The 'interview' often became a mixture of observation and interaction, rather than direct questioning. Four of the 14 people who took part in the study did not use any words (Jennifer, Margaret, Michael and Marilyn), and thus in order to make the person the centre of the research, I tried to prioritise spending time with them, even when this meant some loss of contextual information, although the time spent in direct interaction with the people with profound impairment was brief. I tried to use a wider range of approaches to engage with participants. For some talk was useful, for others doing something together, for others a tape recorder or a drawing proved a stimulus. I learned to be opportunistic and make use of whatever occasion presented itself for exploring an issue relevant to the study. But there were no rules; what worked for one did not necessarily most enable another. As I explain in the following Chapter, communication issues were wider than whether a person used words or not.

I might have difficulties interpreting a person's speech (Sheila and Colin) or sharing their reality (Ruth). I had expected the problem to be lack of time to build a relationship. I think my experience was that many encounters would be brief, for a variety of reasons and that more research sessions would have provided opportunities to try out different approaches and would have increased the possibilities for active engagement by the research participants.

The following Chapter contains extracts from the transcripts and fieldnotes. Below is an example of the way a dialogue could proceed and how I endeavoured to develop a relationship, find out information and also check out my understanding. The example is taken from two parts of my first meeting with Sheila, a hospital resident, whose speech was quite difficult to follow:

- Lisa: So are you alright talking to me, is it alright?
Sheila: Aye
Lisa: You'll tell me, won't you if you get fed up with it? Don't put up with me if you don't ...
Sheila: [not audible on tape]
Lisa: So this place then, this wee quiet room here and then a lounge. You eat together?
Sheila: Aye, eat downstairs, down there.
Lisa: Oh okay, mm, yeah, and then you've got your own room upstairs?
Sheila: See if you go in, in there
... [later]
Lisa: So let me see if I've got this straight. You've lived here a long time
Sheila: Aye.
Lisa: Your mum and dad aren't here any more, so they don't visit.
Sheila: No.
Lisa: You've got three nieces and nephews
Sheila: Nieces! (Transcript 12/1, p. 8 and p. 13).

In the course of the study I came to understand my own attempts to get to know the person as a source of data and I asked myself what barriers I was encountering in trying to get to know them and to be alert to those moments when these were overcome. Therefore I actively used myself and my relationship with the study participants as a research tool. Moments of contact and reciprocity provided data (see next Chapter) and, while they did not elide our differences, I hope that they provided a space of meeting and mutual acknowledgement (Fine, 1994). During the fieldwork I used a number of

strategies to enable the participants to have as much control as possible, such as listening to the ways they might be indirectly providing information or ‘telling’ me that I was on the wrong track, letting them operate the tape recorder, and stopping or stepping back when they were disinterested or had things to do or people present that were more important to them. These were some ways in which I could respond to the power difference between us, acknowledging that this was magnified when people did not use words or could not be fully aware of what research was and how their stories would be used. I tried to attend as closely as possible to the person’s own awareness of their situation. Qualitative approaches do not automatically give more power to the participant, but Corbin and Morse (2003) discuss the benefits of the unstructured interview, ethically and sensitively conducted, as the form that gives them the greatest control; again reciprocity can be a characteristic of the research relations created. My experience with these research participants was that the best approach depended on the individual; for some people short, closed questions and frequent points worked best; for others it was more a case of being responsive to them.

I relied very much on my personal experience with the research participants to ensure that I was behaving appropriately and respectfully, although most case studies were actually collaborations with other people also providing information. Because of the high support needs of the participants, other people were nearly always present or close by. I also discussed sessions with colleagues on returning to the research centre. In practice the main safeguards for the participants were my own ethics and the observations of others. A criticism of my approach could be that it relied too heavily on my own capacity to provide safeguards by being responsive to individuals in order to understand where their interests might lie. The disability movement identifies the involvement of disabled people’s organisations throughout the research process as an effective way to align the research to the best interests of disabled people (Barnes et al., 1999). If I examine the main influences on this research they were not directly from disabled people’s organisations. I set up a steering group which among others included an academic experienced in working with people with learning disabilities and a family carer. However the only organisation that could be said to act for people with profound and multiple impairments was a

parent-led organisation, and I did not feel that this could substitute for the interests of the individuals themselves. It was therefore only individually and through the research process itself that parents were consulted and individuals with high support needs engaged with the research. In retrospect this was a weakness, and an organisation such as People First (Scotland), the independent self-advocacy group, might well have challenged me in a way that could have usefully shaped the findings, and would have included members who had shared some of the experiences of participants in the study, even though there was no group that could be said to represent the interests of all the study participants.

5.2. The policy survey

The method chosen for the policy survey was a semi-structured telephone interview. An interview seemed to me more appropriate than a written questionnaire because I wanted personal opinions and experiences from the interview, rather than formal policy positions that I could obtain from planning documents; it would also give me the opportunity to prompt and follow up on comments. At the time of the survey (1999-2000) some formal consultation meetings were being held by Government as part of the national Learning Disability Review (Scottish Executive, 2000) and I wanted to create an opportunity for informal and frank discussion in which it would be possible for interviewees to talk about any difficulties they might have in implementing national policy.

Telephone interviewing is used less in qualitative than in quantitative research. The main disadvantage of telephone compared to face-to-face interviewing is thought to be a loss of rapport, and therefore of data quality, because of the absence of visual clues (Barriball et al., 1996). However when Sturges and Hanrahan (2004) had to conduct half of their planned interviews by telephone, they found no significant differences when they compared the interview transcripts of the two samples. Novick (2008) suggests that telephone interviews may actually assist the disclosure of sensitive information. Telephone surveys are also more cost effective, especially when the respondents are

dispersed (Barriball et al., 1996). Telephone interviewing was chosen for this study primarily to encourage the participation of interviewees, as it minimised the time involved and could be carried out while they were at their desks. I aimed to keep the interview to 40 minutes and always informed respondents if it was starting to over-run. In practice most lasted about 50 minutes and interviewees were happy to complete the interview.

From the interviews I aimed to establish whether the respondents wanted to develop more inclusive services for people with high support needs, how they would deploy the strategies and technologies available to them, the extent of local capacity to implement change and the factors that would enable them to bring about change. Since the interviews were taking place at a point in the policy cycle where policy development was moving into policy implementation, I was interested in the reasons why policy intentions might become sidetracked (Rist, 1998, Stalker, 1994, Fuller, 1998).

I used a topic guide to structure the interview (Appendix 14). After requesting permission to tape record the interview, I first sought to establish which local planning or strategy documents were currently providing a framework for learning disability services in that area and requested copies. Thereafter, the order of the questions could vary, depending on the initial issues raised by the interviewee, but the sections were: their guiding philosophy or approach in developing services for people with learning disabilities; priorities in developing services for people with high support needs and any expected obstacles in tackling these; the extent of the development of care management and independently provided services for people with learning disabilities in that authority, and how effective they found partnership working to be locally. A closing question concerned the support they would hope to receive from Government as an outcome of the national Learning Disabilities Review.

Most (20) of the interviews were completed by December 1999, two more interviews were obtained the following spring, and then a further attempt to contact the remaining respondents was made, building on the publicity surrounding the publication of 'The same as you?' in May 2000, with a final seven

interviews completed in June 2000. So, a total of 29 interviews were completed covering 28 (88%) of the 32 local authority areas in Scotland; the additional interview was with a special project officer in a health board. The majority of informants were the persons originally identified through the Association of Directors of Social Work as the individual most likely to have strategic responsibility for the development of learning disability services, but in five areas the addressee nominated someone else with more direct knowledge of learning disability services to be interviewed. One of the nominated representatives in an island authority was actually from the health service because the service was jointly organised, and in another area there was a joint general manager of health and social work learning disability services. Although I had used the term 'commissioner' when first writing to potential respondents, many were not yet directly engaged in commissioning external providers.

While the two groups of research participants, the people with learning disabilities and the policy respondents, seemed to pose very different challenges, there were commonalities in the research experience. I had expected to encounter more barriers in making contact with the case study participants, but I found that in practice professionals were not necessarily easier to make appointments with. Organising a time for a telephone interview usually required several attempts because most respondents spent a lot of time away from their desk in meetings and other activities. Where interview appointments were made through an administrator, it was not always possible to check out that the person had been briefed appropriately about the content of the interview. The interview situation did enable respondents to make informal comments, but also made it harder to keep the subject on track, and there was sometimes a lack of clarity in the conversation between services in general and services for people with high support needs. Some respondents would have preferred having more information in front of them, so that they could provide accurate factual information where appropriate. As in the case studies therefore, I learnt to recognize that respondent needs might be different from my own, and that each approach had its attendant weaknesses.

In this section I have described my plan for the research and how I expected to identify experiences of inclusion and exclusion in the everyday lives of the people on whom the 14 case studies were based and the views of service commissioners whose decisions were in part framing those experiences. The next section describes how I tackled issues in recording, analysing and reporting the data and addresses questions of validity.

6. Recording, analysis, representation and validity

Issues of validity and representation are interconnected in this study because I was not able to check back my accounts with case study participants, and so the interpretation of what happened is almost exclusively dependant on my perceptions. In this section I explain how I translated what I saw and heard at each stage up to and including the written text in order to make clear how I arrived at my conclusions.

As described above, the case study sessions took different forms and included interviews, activities and observations. In deciding how to record the sessions I was confronted with the question of how to translate sessions that were a combination of observation and interaction, which for some participants was not verbal. I decided nonetheless to audio record sessions where feasible, and I also took simultaneous notes of spoken interactions which were not taped, for example when I was introducing myself to a family member. These were supplemented by fieldnotes, which were also taped. As soon as possible, after each session, sometimes literally on leaving, I dictated notes into a tape recorder, to which I added fieldnotes in the form of comments, my accounts of what had happened and subsequently, any reflections as they occurred to me. Similarly, when reviewing a case file, I recorded relevant information on tape. All these data items were transcribed and are listed in Appendix 2. Having adapted the research sessions according to the needs and circumstances of the individuals, there is variation in the nature and volume of data for the 14 case studies. Data for any given session may include both interview transcripts and

fieldnotes or, if it was not possible to tape record, then conversations are also reported in fieldnote form.

The translation of the research sessions into verbal and then written media failed to capture the physical presence of participants, and has also written out certain types of information, such as the movements of non verbal participants which, if I had used a different approach such as video recording, would have been available for analysis. However the fieldnotes proved very useful in recording both what else was happening and how I understood the encounter. I did consider alternative methods of recording. For example I discussed with an art therapist the possibility of drawing Marilyn's hand gestures to convey her movements. Similarly I used photographs in some of the early case studies. However, I concluded that seeking to reproduce the research encounter was fallacious, since any form of record is imperfect and an interpretation. Denzin (2001) writes of the interpretive nature of all research media and in an earlier text comments: 'Presence in its full plenitude can never be grasped. Consequently, presence on a tape or in real life is always elusive, shifting and indeterminate; its meanings never final or clear-cut' (Denzin, 1995:9).

Mishler (2003) points out that the form of representation used by an author has theoretical and rhetorical functions, and possibly aesthetic ones too. My decisions to translate the fieldwork experiences into audio tapes and then into written texts are examples of such intentional shapings. The telephone interviews were also taped and transcribed. The translation of a moment of experience into a written transcript flattens out many dimensions; I returned repeatedly to listen to the tapes themselves during analysis.

The transcription of interviews and fieldwork sessions represents an important stage in the translation of fieldwork experience into research text. The tapes were initially transcribed by others, and then the transcriptions checked by me against the original tapes. Respondents to the policy survey were offered a copy of the transcript, but only some took this up. Purposive decisions are made in the work of transcription, even if the process has too often been seen as only a technical task (Lapadat and Lindsay, 1999, Tilley, 2007). In this research one

such issue was whether to transcribe in dialect or not. In one case where I carried out a check and had the session transcribed by two transcribers, one could hear and report local dialect and another not, and the effect of reading the two versions was different. In the end I decided to report consistently across all participants and have reported speech in the text without dialect. As I have indicated, the first steps of analysis began during the fieldwork as, in the course of each case study, I identified a particular issue to pursue and this to some extent determined the focus of subsequent enquiry. Listening to tapes and checking transcriptions also occurred concurrently and helped to crystallise where each case study was contributing new ideas to my understanding of how social inclusion might be negotiated or prevented. As a first step to identifying common themes I engaged in an exercise of data reduction, summarising themes from the material for each study under a number of sensitising concepts (Appendix 5). This enabled me to structure my accounts of the experiences of the individuals, but in a way that still remained largely descriptive. I conducted a similar exercise with the transcriptions of the telephone interviews, and also summarised some quantitative information from these interviews using an Excel spreadsheet.

Having organised the information I identified the analysis themes through an inductive process, returning to the full length field notes and transcriptions for this. I manually coded and indexed the data because this made it easier always to focus on categories in the context of the individual person and their situation. To identify the key characteristics of each case study I produced matrices showing emergent themes, in order to identify shared experiences and important differences. I sought to examine ideas generated through one case study in the others, and so to challenge my initial impressions of the data, although there was not always the data to do this.

While the data from the policy respondents was often diffuse and lengthy, the interactions available for analysis for the case studies were often brief. The fieldnotes often conveyed the immediacy of the experience as I had perceived it, but were limited if I wished to analyse them from another angle. In my analysis therefore, I tried to become conscious of how my selection of specific

issues to focus on in each case study, and my recording of moments that I felt to be significant may have constrained, as well as illuminated, the meanings that I attributed to the data. Particularly when revisiting field notes at some distance of time, I asked myself what had caused me to find certain experiences particularly meaningful. I noticed how such 'moments' could colour all my reflections on a specific meeting, and I was bound to ask myself what aspects of the situation I had not been sensitive to at the time. Mauthner et al. (1998) report on the difficulty of revisiting qualitative data; I also found that whilst I might develop new theoretical perspectives when revisiting the data, there was a limit to how far the data would allow me to pursue these in any depth.

In presenting the data I have used a number of strategies to try and deal with the dominance of my own interpretation at every stage of the production of data. I have taken care, where possible, to analyse and present excerpts as interactions between myself and the participant in order to clarify their contribution to any dialogue. I have been careful to evidence descriptions of situations from the case studies with specific fieldnote references which, although not providing independent corroboration, at least ensure an accurate audit trail for the source of such comments. Fairly extensive fieldnote quotations are given in situations where I am placing some reliance upon my understanding of a significant event. This at least enables the reader to see how what happened affected my consciousness and became identified by me as a significant event. While both transcribed interviews and noted conversations are reported, the form of the quotation makes it possible clearly to distinguish the two. Finally, in the next Chapter, I attempt to demonstrate how far I was able to be attentive to what study participants themselves may have wanted to convey and how I have identified the limitations to my own interpretations. The standards that I have adopted to make my work trustworthy include a clear audit trail and a reflexive approach (see below), taking care to try and recognise my own influence on how the data were recorded, and careful attention at every stage to where my account may be partial and imperfect (Seale, 1999, 2002).

For the case study participants language was not the sole or only way that their experience was made manifest to me, but their meaning was nonetheless

represented to me in interaction. I came to see the data as co-produced between myself and the research participants. This has important implications for the way I have analysed them, as I have looked at whole conversations and interactions, rather than just at the responses of the case study participants. I have drawn upon some of the principles of narrative analysis, although the material is rather fragmentary for formal narrative analysis as the structure of accounts can be hard to discern with participants whose speech does not necessarily follow logical rules. Nonetheless examining such moments of interaction as narrative may make it possible to consider how the interaction has produced the account and, as Riessman (1993:52) suggests, raises the question of how a different interaction may have produced a different account. Narrative analysis focuses on the way in which individual experiences are constituted by social and cultural processes, but I have not approached the analysis from the perspective that there is nothing beyond the story. My own position would be more realist than that described by Goodley when he writes:

The reflexive, embodied, agentic human being is being replaced by an attention to the ways in which (human) subjects and (social, cultural) objects are constructed through a variety of interrelating stories and practices: or discourses (2004:102).

For the policy implementation interviews with service commissioners, my focus was always more explicitly on their discourses around inclusion and high support needs, how they defined such terms, and what commissioning decisions they made on the basis of these. I was interested both in how new categories of need might be being created and the relationship between views on inclusion and the decisions made about service developments. I sought therefore to examine how the discourses of need and resources intersected and might determine the provision that was commissioned or developed.

In disseminating this research I have had some opportunity to move beyond a written text. I was able to apply some of the experience gained in this study by contributing to the production of a resource aimed to change attitudes to people with high support needs. Two voluntary organisations commissioned a video maker to produce a DVD of four stories of people with high support needs. Two of the individuals from this study participated and I wrote the accompanying

guide (Curtice, 2003). It was disappointing that the two participants in my study were not well enough to attend the conference at which the resource was launched, although I did take a copy of the DVD to them later.

Thus I have made strategic selections at every stage: in identifying people for interview; in deciding who to speak to and where to observe or visit; in identifying issues to pursue; in attending to particular aspects of the encounters between us and seeing these as significant; in drawing out themes which I see as providing analytic purchase and finally in interpreting these from particular theoretical stances. I have made these decisions explicit because, with some exceptions described in the next Chapter, participants are not able to challenge the account that I am providing of their situations and experiences.

7. Towards a reflexive account

In this section I attempt to provide a reflexive account that will address the question of how, who I am, may have influenced the research (Mauthner and Doucet, 2003). I intend that the exercise should assist me to perceive the particular ways in which my account may be partial and limited. As Butler (2005) suggests I must ask, who might have got a different story from the one that I have created. By considering the extent to which my research account is affected by my own biography and is socially situated, I hope to be able to make explicit some of the influences and processes that may have led me to ask, understand and express some things, and to overlook others. However, the value of reflexivity is not merely to recognise the limitations to one's work, or only to reflect upon the effects of personal perspectives. The purpose of reflexivity is to go beyond personal confession and to identify and change exclusionary practices, both of our own and of society; a reflexive account takes its place as part of a critical engagement with others about how to change practice.

The initial impetus for this work was an awareness of the position of people with learning disabilities as a question of social justice. When I took up a post in a community care research centre, a visit to a long-stay hospital for people with learning disabilities made me aware of the segregation and exclusion experienced by people with learning disabilities on the outskirts of the city where I lived. With the benefit of hindsight, I now see that the issues of citizenship and responsibility, which I initially put forward to frame the subject of the study, also reflected my own concerns about how I should respond as a citizen to this experience. As Young argues, claims for social justice are not theoretical, but rather claims made upon some people by others: 'Rational reflection on justice begins in a hearing, in heeding a call, rather than in asserting and mastering a state of affairs, however ideal' (Young, 1990a:5).

So, having felt that a claim had been made upon me, and that a response was required, I therefore approached the research with an explicit commitment to challenging the exclusions of people with learning disabilities who had been cut off from mainstream society. I am aware of the risks that are considered to accompany a committed stance. Silverman points out that the risks of having a political or moral agenda may include a tendency to find data to support the preferred position (2001:265), whilst Hammersley considers that those who seek to use their research to bring about social change may exaggerate how much influence research can have on policy and practice (Hammersley and Atkinson, 2007).

The way in which my positioning affected the conduct of the research was that I sought to translate this broader concern into a research question, and to explore what was needed to overcome the barriers to inclusion in research. This meant that I prioritised the time I spent with the research subjects themselves, rather than in listening to other perspectives. This may be considered justifiable insofar as the inclusive research enterprise has to date not engaged fully with people with high support needs and/or no speech. As Tim and Wendy Booth (1996) note, the desire to reinstate the 'excluded voice' has developed from feminist research and critical race theory. Thus, the desire for social justice can intersect with methodological concerns.

I viewed my position as that of a citizen researcher and believed that a mainstream researcher should be able to engage with the social issues arising from the inequalities experienced by others, whoever they are. However, this could be questioned in the same way that research by people of one gender, sexuality or 'race' on another may be problematised. A fellow participant at a Disabilities Studies Conference in 2001 remarked: 'You might have been better working on Poverty Issues'. She was alluding to the fact that I was not a disabled person. This was my first attempt to carry out research with people with learning disabilities, although in parallel with it, I led two collaborative studies into the health needs of people with learning disabilities. It was also through this research that I had my first personal encounters with people with learning disabilities, apart from occasional contact with a relative by marriage. During the years since this research started my own health status has changed, and I have developed a lifelong limiting condition and a visual impairment whilst writing up. However, I am not at all sure that this means I am any more or less qualified than before to conduct research with people with learning disabilities. Within disability studies there is increasingly a recognition that defining ourselves exclusively in terms of fixed identities may limit our capacity to acknowledge shared vulnerabilities, and therefore identify common interests (Shakespeare, 2006). Butler writes of the limits to self understanding and reason as 'not only the condition of the subject but the predicament of the human community' (2005:85). My attempts to write a Ph.D. at this stage of my life have brought home to me the impact of age, the variation between individuals in characteristics such as capacity and competence, and the problems of depending on fixed identities and labels.

My resolution to the problem of being a novice in the field was to position myself as a learner. I write in the next Chapter about how I felt that the research participants were demonstrating to me their expertise about their own lives. However my concern to get alongside the study participants and my own belief, that in Colin Barnes's words, I was 'for the oppressed', rather than 'the oppressors' (1996b), may have led me to be less aware of the differences in power, and the social distance between myself and the research participants. A reflexive stance acknowledges that the researcher is part of the setting they are describing (Altheide and Johnson, 1998). In analysing my data I have become

aware how differences in gender and age may have made it harder for me to build a relationship with some participants than with others and that this affected how much I was able to learn about their lives and understand what mattered to them. For example, I was much more at ease making small talk about clothes than about football, and I undoubtedly missed some opportunities to pick up references and build a rapport with one of the younger, male respondents. As a middle-aged, female researcher from England my life experience contrasted sharply with that of most study participants. I was in my 40s, whereas some of the study participants were half that, closer in age to my daughter.

My life had been lived free from intervention by the welfare state and my identity as an adult had been built on access to educational opportunity. I therefore have to ask myself how the study participants may have perceived me and how this may have affected how they engaged with me. One participant's family member did tease me about coming from a very different part of the city, but many of the participants who were not in position to analyse my status in terms of class might have been aware of differences in dress, accent or ways of speaking, and I presume that they may have associated me with other professionals they had met. The importance of this is that it underlines the power imbalance in the relationship between the research participants and me, suggesting that my view of the research experience as one of mutual learning and co-production may not take sufficient account of the far greater control that I had over the process. Reflexive ethnography demands an awareness of the cultural hegemony that can be exercised in misinterpreting cultures through the lenses of one's own (Davies, 1998).

Humphrey reached the conclusion (2007:22) that to produce a full account of her research she had to write about the way it had caused her to re-evaluate her own identity, because she discovered that 'truth of the self is integral to truth of the study' (Ellis and Brochner cited in Humphrey, 2007). She came to make productive use of the tensions she experienced in moving between an academic and an activist world, by developing a narrative that translated between the two, and she helped me to appreciate that I had to be able to recognise what was happening to me in the course of the research in order to be able to give an

authentic account. I would characterise my own journey as a sometimes uncomfortable progression to a position of influence in the field of Learning Disability in Scotland, a position in which I have tried to maintain my accountability to people with learning disabilities by ensuring that their views and interests both inform the work for which I am responsible, and influence the work of other agencies in the field. The way in which writing this thesis has challenged me is that it has made me engage critically with the place of my own authority/voice within the wider field. In tune with Davis (2000), I reject a 'them and us' characterisation and favour dialogue in which there is room for contributions from both the researcher and the researched:

Central to this discussion has been the concept that respondents are the experts on their own lives, but that ethnographers possess expertise which can be utilised in a variety of ways to contribute to processes of change (Davis, 2000, p.203).

I have had to take responsibility for my own work as a researcher and a writer, in collaboration with, but not exclusively dependent on, the views of people with learning disabilities themselves. This has both confronted me with the need to recognise the power I have as a professional and to be clear that in this thesis the voice I speak in is as a sociologist. At the same time I have come to acknowledge the partial nature of my own authority, which must itself become the object of reflection and inquiry.

One of the barriers to having Learning Disability seen as a mainstream inequalities issue, is that certain professions and organisations claim ownership of it, thus underlining a lack of control by people with learning disabilities themselves. I experienced this professional gate-keeping as soon as I started to undertake research in this area. For example, when visiting a community learning disability team to introduce another study, the first question from the psychologist, speech therapists and others concerned my credentials for working with people with learning disabilities: 'So how come you are working in Learning Disability? Do you have a family member or were you a nurse or something?' Throughout the time since then, I have had to engage personally with questions of authority, representation and power. The encounters in this research formed part of the reason that I left university employment to set up the Scottish Consortium for Learning Disability to support the implementation of the policy

whose beginning I had been studying. That organisation has had a focus on building respect for people with learning disabilities by demonstrating the contributions that they can make as citizens. In this organisation power is shared with people with learning disabilities and carers, but the organisation is not user-led. I have therefore travelled in the course of this work from 'outsider' to 'insider' status in the network of Learning Disability policy and practice in Scotland, and from a more private to a much more public position in the field. This has been personally empowering and I have also gained in autonomy, salary and status, whereas during this same period there has been little change in the life circumstances of many people with high support needs.

In consequence, as I write up this research, I have access to the policy process in ways that are not always available to researchers, and this puts me in a stronger position to influence change than when I started the research. However I am aware that proximity to government and receipt of funding from it may also compromise my capacity to identify any messages in this research which may contradict current policy, as my responsibilities for the implementation of the policy agenda may have led me to internalise the assumptions behind current policies and strategies. A counterbalance to this is that after eight years in a role of trying to effect change on the basis of the policy whose development I describe in this study, I have become aware of the limitations of trying to implement inclusion without an understanding of the reasons for exclusion. I need more than ever to understand and to communicate how this research fits into a wider picture of how to effect change for people with learning disabilities and high support needs.

I do not expect a direct impact on policy from the research, but I appreciate the value for policymakers and practitioners of a better understanding of how to interpret the interests and, if possible the views, of people routinely excluded from direct participation in the policy process. I am therefore writing this thesis because I cannot not write it, whilst acknowledging that it can only ever be a contribution to a larger whole.

8. Conclusion - ability to address research questions

In this chapter I have tried to indicate some of the challenges which I had to attend to as a researcher, and the manner in which I have dealt with these. I began the fieldwork for this study dismayed that the time I could spend with participants with learning disabilities and high support needs was to be restricted. My experience of the research in many ways confirmed my view that this was to misunderstand the requirements for ethical and effective work with people with high support needs. In the first place the capacity to build a relationship was central to being able to communicate, and this was more important than a fear of intrusion. Informal time together is needed to get to know a person and this may take longer in the case of someone with high support needs than in building some other relationships. Moreover, flexibility is essential to being able to work respectfully with people with many health needs; when planning research I now allow for three attempts at contact for every one I would make in a standard research design. In other ways too the issue of intrusion raised by the research ethics committee posed important questions which I continued to put to myself throughout the research. Since Goode (1994) conducted his pioneering work, the idea of the ethnographer living unobtrusively as part of a culture has been challenged from many stances, most notably in requiring the ethnographer to be reflexive about their own role in creating the data and aware that that they are interpreting a setting rather than merely observing and reporting on it. In the course of the study I unlearned some tenets of my research practice and, through the process of learning to attend somewhat better to people with learning disabilities and high support needs, became more conscious of my own positioning and challenged to examine my theoretical stance and the political implications of my practice and writing.

In the next chapter I illustrate the ways in which the study participants made themselves known to me, I show how they found a variety of ways to convey their individuality, and I continue the theme of the competencies required of an inclusive researcher.

CHAPTER FOUR Moving Beyond Categories: Relationship, resistance, and recognition

1. Introduction

In this chapter I will introduce the individuals in this study, explore ways in which they transgressed the categories and labels assigned to them, and discuss the implications for research practice of the issues I encountered in trying to get to know them. The main themes are the effects of the relationships within the research on the data that I produced (relationship); how my interpretations were challenged and destabilised by counter-narratives from participants (resistance); and the implications of the research process for possibilities of a transformed view of the research subjects (recognition). I will consider the data as narratives which, when produced from what I term an 'attentive' research stance, have the potential to recognise the research participants as subjects with agency.

The concept of Narrative is central to this chapter. As Stanley and Temple note (2008), the 'narrative turn' comprises different theories and approaches, but narrative describes how lives come to be interpreted through the stories told about them; in this context a 'story' is a particular narrative about a life. Consideration of life as narrative provides me with a position from which I can ask questions about how particular versions of the lives of research participants came about through the interaction of the research relationship, for 'narratives are always contextual, communal, and relational, and there are always subjects making claims and counter-claims in, through and about the stories told and accounts made' (Stanley and Temple, 2008:278). I acknowledge that the accounts that I give of the research participants are necessarily partial and unfinished and that the data that I have created are themselves texts that I need to interpret reflexively as situated narratives that contain the influences and emotions of the time at which they were created (Silverman, 2001 p. 113, Layder, 2006 p. 279).

Whilst I am interested in the way that particular perspectives on the participants were created through the social relations of the research, I recognise that, in Atkinson's phrase 'narrative is but one form of social action' (Atkinson, 1997: 343). The research participants and I encountered each other as embodied persons, not as texts (Burkitt, 1999:2). Turner (2006:494) defines embodiment as the physical practices that give a body its place in everyday life and I am interested in how I could act alongside the research participants to transform social and power relations. Foucault proposes that the study of resistance to specific forms of power is a good starting-point for delineating the processes of power relations. In his commentary on 'The Subject and Power' (Foucault, 1982:208), he identifies the relationships between knowledge and the exercise of power as fundamental to how people are made subjects and argues that consideration of the interaction between capacity, communication and power is necessary to understand how power is exercised (1982:218). I will consider how the research process may have structured the capacity of the research participants to contribute and I will demonstrate how they also acted to co-create narratives that challenged labels of incapacity and incompetence.

I illustrate my arguments with the two forms of data that I created during the research. The first consists of transcripts of tape recorded conversations and encounters which I can use to analyse verbal exchanges. I agree with the emphasis which Low (2006) gives to communication difficulties as an outcome of the interaction between the researcher and the informant. There was wide variation in the extent to which words formed the communication medium of the participants, but strong statements can be made in few words (Booth, 1996) and are still susceptible to analysis. The other data comprise fieldnotes, also in the form of transcribed tape recordings, which were made as soon as possible after the events they describe. These take the place of transcripts where the interaction taking place was largely non-verbal or the tape recorder was inappropriate and also record my reactions and reflections as I tried to make sense of what was taking place. I will use these as material to examine my own changing perspectives and to reflect critically on the status of the narratives that I produced.

Plummer has noted that particular types of stories emerge when there are social audiences or 'interpretative communities' (1995:46) ready to hear, develop and sustain them. Feminist writing on the gendered body, for example Young, (1990b), Haraway (1992) and Bryan Turner's work on the vulnerable body (2006) I see as having prepared the ground for hearing new stories about 'incapacity' in which different forms of being in the world, negotiating reality and communicating can be recognised as part of a reciprocal ethics of interdependence. Bryan Turner writes that: 'Recognition of the Other entails recognizing our mutual vulnerability and this recognition opens up new possibilities for social solidarity' (Turner, 2006: 96). The research process positioned me as a listener and affected my emotions. I experienced capacity and incapacity as shared possibilities, rather than as distinguishing categories and so I want to consider the implications for developing solidarity, both in research writings and in writing (in)capacity.

I will now provide a brief synopsis of the different sections of this chapter. In Section 2, 'Storied selves', I describe the different ways in which participants made themselves known, including telling me about their lives, demonstrating what they wanted me to see or hear, taking charge of the recording equipment for their own purposes, and through their physical presence. In Section 3, 'Communicative Acts', I discuss in more detail the communicative environments created in the research with particular reference to my experiences with people who challenged my communication repertoire and my understandings of disability. I note that communication was not a purely technical issue and that different social and material factors affected the possibilities for the research participants and myself to understand each other's meanings. In Section 4, 'Acts of resistance' I give examples of ways in which the research participants subverted the categories assigned to them, resisted attempts to impose unwanted meanings on their lives and challenged my attempts to make them into research subjects. I argue that opportunities to reject, contradict and disrupt the assumptions of others may be an important part of the conditions for research participation. I conclude this chapter in Section 5, 'Recognition' by

reflecting on the effects of the research relationships on my position as researcher and how the research could challenge disablement.

2. Storied selves

In this section I discuss the different ways in which people conveyed who they were and I sought to find out about their lives. I illustrate how people acted as informants, told stories about the past and demonstrated aspects of their personality. I also highlight how I was introduced to some people with profound and multiple impairments through their presence and the accounts of people who knew them well. There were differences in the capacities of individuals to contribute directly to the research, but all challenged the label of 'incompetent' research subjects because their inclusion in the research revealed important aspects of the material and social relations of their lives. I identify themes in the narratives including responsibility, the importance of past experience and the place of family relationships. I note that all the accounts were provisional and the 'stories' I present subject to interpretation. However I see them as part of a continuing dialogue to reclaim personal experiences of disablement.

2.1. Claiming responsibility

Responsibility was a theme in several people's stories about themselves. For example, Mairi told me about herself in ways that emphasised her responsibility as a family member. According to the support workers, Mairi's sister was her carer, but this is not how Mairi saw it. As Mairi explained, she was the elder sister.

- Mairi: My sister is 3 year younger.
Lisa: Right, okay, she's in her mid thirties.
Mairi: And I'm the big sister.
Lisa: Right. (long pause)
Mairi: I am the only sister she's got..
Lisa: Right, right.
Mairi: So I'm the big sister (Transcript 11/2, p. 2).

During the four sessions that I had with Mairi I was able to corroborate the impression of responsibility that she conveyed, by seeing her check the time for her tablets and arrange with her support worker to go and buy a card for a family member's birthday. But I had not seen the whole story, and a chance encounter with Mairi one Sunday in the local Accident and Emergency Department showed me that epilepsy was having a greater impact on her life than had been apparent to me in our meetings. Mairi was being collected by her sister. She had her clothes in a clear plastic bag and was looking somewhat distraught. Apparently she had had 'a few turns', and so they had not been able to go to church. Her claim to be the one in charge was fragile; she and her sister existed in interdependence.

Mairi acted as a guide to me in the research, making sure that I was informed and got the facts right. For example,

When I asked her where the meeting was next Tuesday she wasn't able to remember and later on she said to me, well, you know, she'd look at the letter again and write down the name of the place so that she could tell me (F/notes 11/1, p.8).

It was easy to identify in Mairi the attributes of a valued research informant. An informant is more than a respondent who answers questions. The informant is an insider, guide and translator who helps gain entry to a culture and social network and identify other contacts (Fontana and Frey, 1998 p.59). The well-informed ethnographic informant, according to Johnson (1990) will possess attributes such as access to information and knowledge, in order that they can know, recall and report accurately. Mairi exhibited responsibility in her social relationships and was a resource to the research. Her life was also vulnerable to disruption and she had to rely on others. In my interpretation, her story illustrates the interdependent nature of social responsibility.

2.2. Recalling the past

Of the study participants Stuart and Ailsa most closely approximated to oral historians and autobiographers as they appear in the accounts of Atkinson,

Walmsley and others (Atkinson et al., 1997, Atkinson and Walmsley, 1999, Walmsley and Johnson, 2003). Both Stuart and Ailsa wanted me to help them create an account of their lives and seized upon my tape recorder as an opportunity to put important memories on record. Stuart had lived his adult life in long-stay hospitals and secure environments. His personal history was bound up with the history of these institutions and he recounted stories that illustrated the place he had held within them, for example in an anecdote about the State Hospital:

That's a new place we've got up there in Carstairs now, brand new one. There's 235 residents in it, five doctors, but the cameras are going round all the time. Everywhere the patients go, the cameras are in the toilets and everything, bathroom and everything, all over the place. It used to be my big field for growing potatoes in, but they took it away from me and they put that in. I had a nice big garden with tulips and everything in it. And they bulldozed them all down. I was like, "where's my money?". I told [name of Doctor] about it. He says, "you'll get your money off", he says, "don't worry about it!" (Transcript 13/1, pp. 25-6).

Two recurrent themes of his stories were, respectively, that he was a strong man and that he was well respected by those in authority; both themes could be seen as reflecting his long years of institutionalisation. He too told of responsibility and said that his job in the prison hospital had been to look after the kitchens and that, following some attacks on staff, he had kept a very careful check that no knives went missing.

Stuart: There was I looking after fifteen kitchens up there.

Lisa: Oh my goodness.

Stuart: Big kitchens, not wee ones, big ones. I had to go round and check the cutlery every so often and round the OT's [occupational therapy unit] tools and come back again, go round again, double check again at the last minute at night. I continued that year in and out ... And anyhow I used to say to them "Put the knife down or you'll get a needle. If you don't put it down I'll tell the doctor on you, how bad you are to staff members". "Ah but you're a patient just the same as me". I says "I know that but I said I'm head kitchen man son. Don't you forget it." (Transcript 13/2, pp. 11-12).

As the hospital closed around him he was very conscious of the people he had known there who had died. His interest in having his story put on tape was not only backward-looking. He was a member of a collective advocacy group and took it upon himself to be concerned about the arrangements for people who

had already moved out of the hospital. He wanted me to make multiple copies of the tapes so that they could be given to people on the other remaining wards and to those living in the community. I thought of Stuart as a bard, recording a culture that was passing for those to come. Like the living poets recorded by Neat with MacInnes (1999) in the Highland and Islands of Scotland, bards are transmitters of oral culture, who praise the dead and sing of the brave deeds of the past. They may be unknown outside their own communities and yet they are honoured there as tradition-bearers.

However Stuart's account of his personal history was selective. He recounted incidents from his childhood, such as making candy apples and selling them for fourpence so that he could go to the cinema, but he referred only obliquely to whatever sexual offence had led to him being detained for so long under Secretary of State's orders, although he spoke with regret about the distress he had caused his parents. Stuart had lived with the consequences of a long-ago offence. As I see it, he wanted to use his position as a person with experience in the community of the hospital to retain his position as a leader, after the institution closed, but also to help his peers with whom he felt a strong bond of solidarity.

Whilst Stuart consciously told of his memories of a closed society, Ailsa also used the research as an opportunity for more personal oral history. She was also a patient who was detained under the Mental Health Act, but was living in a health-managed facility within the community. She also both celebrated and mourned her personal past and sought to keep alive connections between it, the present and the future. 'I'm a great laugh!' she declared affirmatively, and indeed she was. Ailsa used the tape recorder selectively, turning it on and off to mark the distinction between times when she wanted to record what she felt to be important about her life experiences and social time when we were chatting together or having tea. A survivor of sexual abuse, she particularly wanted to create a record of both the 'good times and the bad times'. I had a sense that this was a way in which she could put her mark on the world and affirm the importance of the people who had been important to her.

A: What you should do is.

L: Yes, yes.

A: What you should do is.

L: Mm.

A: You should write a story about (pause) about all the bad times and all the good times.

L: Yeah good idea.

A: All the bad things that I had with my parents, all the good times that I had with my foster parents, all the good times I had with Sally [in a potential adult placement].

L: Yes, yes.

A: Sally's family.

L: Yes. Okay that would be good wouldn't it? Be nice (pause) then you can have it to keep. Yeah. Yeah.

A: That's a lovely story, isn't it?

L: Mm. It would be a lovely story.

A: And you should put Ailsa on your book.

L: Write the title.

A: Mm, hm.

L: What would it be, like Ailsa's Story or ...

A: Ailsa's Story, Life Story.

L: Oh yes, okay, yeah.

A: And inside, this book belongs to Ailsa about her bad times and her good times. All the bad times and all the good times and I can write all that. Write on the, write on the (pause) bad times and put on the good times (Transcript 17/3, p. 9).

As Atkinson suggests (2004) committing her story to the record may have been for Ailsa a way of integrating and affirming her experiences and, by extension, herself. The record of her story was to be primarily for her own use. Stuart and Ailsa were deliberate storytellers, and both enlisted me to act as the recorder of their stories. The power of their accounts shows that their legal status did not entirely define who they were; for they made ballads out of their past experiences. Both displayed resilience which Goodley (2005) has identified as an empowering quality in the narratives of self advocates. My interpretation of the meaning they conveyed by their stories would be that the past still acts on the present but can to an extent be remade and therefore may not wholly determine the future. Thus their story-making could be seen as a liberating act.

2.3. Demonstrating personality

Another way in which the research participants showed me aspects of themselves and their lives was by demonstrating them. For example, Rob spoke little, often covering his face with his hands. Meeting with him was also strictly controlled because he was considered to pose a risk to women. Although he was quite wary of speaking himself, he was keen for me to hear certain things about him and he encouraged his support workers to talk to me about things that happened. For example when we met in a pub he asked his support worker to tell me a story about horse racing which was that once, when his support worker had been passing a betting shop, he had pulled a face and said 'Horse racing! Ugh!'. Now, whenever they went past a betting shop with a picture of a horse, Rob always exclaims 'Ugh!'. So I felt that he wanted me to think of him as a comedian. Another way that he found to introduce himself to me was to show me round his flat. I was taken on a grand tour of the flat, with Rob abetting his support worker.

Rob came round with us and sort of kept gesturing, extending his arm out to say, you know, 'And look at this'. And he wanted me to see absolutely everything. They both did really.... On the right there are two bedrooms. One of them is Rob's room and they took me in there. Initially he put his hands over his face when I went in there and I was about to back out, but actually he was very keen to show me round and he opened his wardrobe and showed me all his clothes (F/notes 6/3, p. 5).

In the course of the evening he presented a number of demonstrations of who he was and what was important. He made several phone calls while I was there, to relatives and to the hostel he had previously lived in, and he played me a CD of his music that I had shown an interest in. Rob exhibited the parts of life he wanted me to admire and he successfully impressed me.

If I had to sum up how Tracey presented herself, I would put it into the phrase 'I'm a star!'. Despite the concerns about her vulnerability that dominated her care package, she wanted to convey her own confidence in herself. The young woman I met was a born performer, for whom singing and dancing were her chosen ways to express herself. I observed this one day in the day centre.

Later on when an old song came on that she really liked she said, 'I want to sing along to this', and other people were quiet as she sang. And her eyes and her face just lit up, she was completely transformed when she was singing and dancing. She was really, really into it. It really seemed an expression of her and her personality (F/notes 7/6, p. 4).

One day Tracey made use of her talent apparently to participate in the research on her own terms. Christmas was approaching and she was enjoying the preparations. In a moment when her support worker was elsewhere she found a way of being a research subject that matched her strengths and interests, or so at least it seemed to me. In my fieldnotes I recorded what I felt had taken place.

So when we were upstairs alone in the aromatherapy room, Tracey sang into my tape recorder. And first of all she sang, 'We wish you a Merry Christmas'...She sang it out of tune, quite close to her speaking voice, whereas normally she sings perfectly in tune, which was interesting. She was also transposing words, she was saying... 'We Miss you a Merry Christmas' and doing that consistently, even though I asked her to do it a couple of times.She then sang something else, and then, finally, was asking me something that she could sing, so I suggested her favourite 'You're my Barbie Girl'. ..But in the course of this song, without a flicker, she began to answer the questions that I was implicitly asking her. So she kept the tune, and then she was singing, 'this is the Smithstown Centre, it's a good place, people are going to the pantomime they are going to be happy and Philip is my pal' (F/notes 7/9, pp. 1-2).

I construed Tracey's action in the light of what I already knew about her. In my view she had managed to translate the research questions into a medium that she felt comfortable with and she took control by performing in the way that she was most skilled. Like a true professional, she read her audience and reached out to them, winning their applause.

Both Rob and Tracey managed to convey aspects of their personality in spite of the constant supervision that they received. They showed that people can take up the mantle of research subject in unexpected ways. Yet I was possibly too ready to assume that their purposes matched my own. At the time I interpreted Rob's eagerness to invite me as indicating trust in me and therefore representing a success in gaining access; but it is also possible that for his part he saw the visit as a rare opportunity to meet a woman. Tracey may just have wanted to

have fun. Their stories had a purpose and I learnt from them about the aspects of themselves that they may have felt were not given enough opportunity for expression.

2.4. Testifying to value

Margaret and Jennifer were both young women with profound and multiple impairments who lived at home with their family. I will describe how I first met Margaret to illustrate how accounts from people in close relationship with the person could help to create an impression of who that person was. I first met Margaret through her mother's descriptions of her life and this introduction to her as a valued and loved member of the family provided me from the outset with a context in which to see Margaret as a person with relationships and individuality. I met Margaret gradually, first through her mother's words, then through pictures and finally in person. This gradual approach was probably deliberate on the part of Margaret's mother, whose experience seemed to have led her both to 'test' and prepare people for meeting her daughter. It was only very late in the meeting at her home that she showed me pictures of Margaret. In the field notes I remarked that I realized that she had sat me down at first with my back to the drawings of Margaret. I felt that she was making sure that I understood how loved and valued her daughter was before 'introducing' her. Subsequently Margaret's mother took me through the wall of family photos. At the end of the afternoon Margaret returned from the day centre and I was able to meet her myself in her home.

She said that it was important that looking nice was a stepping stone and at that point she showed me two drawings, one in charcoal and one in felt tip, that were on the wall behind me, they had been mounted in frames and they were pictures of Margaret and they were very, very nice and her face really, one of her asleep and one of her awake...and then she took me through the wall of family photographs. It was quite interesting that this had all happened really quite late in the interview. I don't know who she was preparing for the encounter of this picture of Margaret. She had sat me facing away from them when I came into the room. She almost deliberately sat me down and I'm not sure quite whether she was testing my reaction or what, but anyway, she took me through the family photographs and these were really very interesting and remarkable because they demonstrated how much Margaret was a part of this, not apart from, a part of this

family. They were the classic photographs of weddings, christenings, first communions and Margaret was there. There was Margaret's first communion with her in the dress, in a beautiful dress. ...

She was making me a cup of tea when the bus arrived bringing Margaret home, so I was able to meet Margaret ... While she was in her chair her mother was standing beside her, they were touching hands, her face completely lit up at her mother and her mother's voice, there was a lot of contact and interaction. She was introduced to me, it was explained that I wanted to come and see her and so on....She was certainly very, very intensely aware of the interactions between people and so on and was very accepting of me...

One phrase I forgot to mention, when her mother was talking about how she tried to make Margaret look nice, was she said that 'you had to have pride in the person and love' and it was really, clearly demonstrated in the interactions that she had both those things for Margaret (F/notes 2/1, pp. 9-12).

Experience had made Margaret's mother highly conscious of the importance of a good first impression for ensuring that Margaret was valued by people she met. She invested in her appearance and I believed that she had managed the moment at which I would see a picture of Margaret. When I was able to meet Margaret I had already been told how important family relationships were to her, but she immediately demonstrated this herself.

Michael, a young man in his late twenties, had very profound impairments. He was present when I visited his parents to seek consent for the study, but was asleep for most of the time on the sofa. Michael was also asleep the first time I visited the day centre to meet him, although I had better luck on the second occasion. I was never alone with Michael, indeed his complex epilepsy meant that there were always two people with him. Michael's physical presence was therefore one way of knowing him, but I was dependant on others to interpret for me and I relied on proxies, his mother and support workers, supported by artefacts such as photographs, and his case records to understand about Michael's life. From his mother's description Michael emerged primarily as a much loved family member and this was borne out by pictures of him at a family wedding. Thus one way of knowing Michael was, as with any other person, through his social relationships and this was the way I introduced him on a public

education DVD that I was subsequently involved in making and on which he featured:

This is the story of a much loved and valued son and brother who lives at home in his community and receives support because of his profound learning disability and complex health needs (Curtice, 2003).

My sessions at the day centre consisted in simultaneously speaking to his support workers and observing their interaction with Michael. One worker, Stew, had known Michael for many years and was with him all day for several days a week. Stew felt that he could interpret Michael's movements and this enabled him to maximise Michael's autonomy, giving him small choices, for example in eating. Stew also felt that Michael co-operated physically, for example in getting into the taxi and for Stew this represented the reciprocity of their physical relations and how they worked together:

Michael knows, Michael knows people, it's amazing the amount of things Michael can do. If you were probably to meet Michael the first time, you would think Michael's quite severely disabled and Michael is severely disabled. Michael's got so many things going for him - and sometimes he can make it very, very easy for you (Transcript 8/3, p. 5).

To my view, in his description Michael's body became a 'productive body' (Burkitt, 1999), capable of exerting influence over his environment. This contrasted with the way in which those commissioning his care (see next Chapter) had problematised his body, seeing Michael's uncontrolled epilepsy and tendency to bump into people as risks that the day centre might not be able to contain.

It was important to me that I met Margaret and Michael in person, even though I also needed others to tell me about their lives. The images that Margaret and Michael's mother showed me and the stories that they and Michael's keyworker told me seemed purposeful, intended to show how the person was loved. Thus their accounts were not simple descriptions, but testimonies of why the person should be valued and I should treat them with respect. I took this to imply that they had constantly to struggle to maintain a positive image of their loved family member in the face of hostile reactions from strangers, based on appearances.

2.5. Stories in context

I have shown that the study participants often knew what I was about, demonstrated initiative and creativity in the research encounter, made active use of the occasion and broadened the communication media used to convey meanings. They employed a range of styles to tell their stories and sought in different ways to make sense of their relationship with me. Stories of the past, news of the present, visual images, singing, jokes and demonstrations were amongst the ways in which they conveyed meaning. My tape recorder became a tool that some participants seized upon as a way of taking some control of the encounters. Ailsa, a karaoke veteran, experimented the furthest with this, speaking deliberately into the machine when she wanted to emphasise the statement that she would like to have set down. Instances like these suggested that the tape recorder could provide participants with a useful third party to our encounters.

The dramatic potential offered by the research situation enabled some participants to reveal their capacity for meaning-making and to challenge their disablement. They could be bards who celebrated a time that was passing, informants who showed that they knew more than might be assumed and performers who dramatised their lives. There were a number of ways in which their accounts could be seen as liberating. For example Stuart was a restricted patient whose status was delaying his discharge into the community. Nonetheless his memory of the past and his concerns for his peers revealed him as a powerful advocate whose life experience made him an authority on the issues affecting long-stay patients. Mairi and Rob challenged dominant narratives of who they were and Tracey found ways for her own voice to come through a carefully managed regime. Ailsa accepted both the good and bad things that had happened to her and, in so doing, affirmed her resilience as a survivor. Margaret and Michael made their presence felt through social and physical relationships. All these statements could be read as dismantling the conditions that produced disability from their experience.

These experiences raise questions about the designation of some people as ‘incapable’ research subjects. It may be easy to underestimate the potential contribution of people with learning disabilities, and especially those with high levels of impairment, to provide valuable information for research. Intellectual capacity is not the only criterion for successful research participation. The research encounter involves a personal interaction in which it is possible for information and understanding to be transacted by various routes, including affective responses. By ignoring the contribution that can be made by people who do not conform to the mainstream criteria for a ‘good’ research subject, the process of disempowerment and disablement is reinforced.

I saw the people about whom I made the stories as embodied, as realised in social relationships, and as able to remake past experience and to influence their present environment. I did not ‘capture’ the identities of the participants in my research, nor did they ‘reveal’ the essential nature of their lives, but the stories we made together can be powerful because they can help to rewrite dependency and incapacity, not as fixed states or signifiers of difference, but as relations which are susceptible of change.

3. Communicative acts

In this section I want to look in more detail at the interaction between myself and the research participants through examining the process of communication within the research encounters. I will give examples of the communication issues I encountered and discuss the extent to which my approach enabled or prevented individuals from ‘telling’ their stories. I conclude by reviewing what I learnt that might improve my research practice in order to better enable their contribution. Communication was a social process and the communication issues that I identify are wider than the use of particular communication techniques.

3.1. When meanings are uncertain

The first issue I want to discuss is that of responding to communication which may not be intentional. I will illustrate this by my first meeting, early in the research, with Marilyn, a young woman with profound and multiple impairment who did not use words. The main issue for me was that it was difficult to be sure when her communication was intentional because she spent a great deal of the time making gestures that seemed to follow a regular sequence. This created a number of tensions for me: it appeared to throw into doubt my capacity to know what she felt and this introduced considerable uncertainty into any account I could give of what was important to her. It also confronted me with the physical manifestation of impairment-effects whose implications for cognition and communication I did not understand. However I was to learn from Marilyn that the effort of trying to communicate with her on her own terms was worthwhile and that I would have to let go of my own assumptions that every interaction was significant or had a meaning that I should be able to decode. Therefore the 'problem' of her communication could be reframed as my discomfort with uncertain meanings.

Marilyn lived in a supported living project. I was able to meet her in person before other people gave me much information about her. On that first occasion I was invited into the living room and the staff left us alone, so she was immediately presented to me as a young woman whom I could get to know directly. My initial focus was on her complex pattern of gestures, because it seemed so integral to how she was in the world.

Marilyn came down stairs and sat on the sofa. She had on a red top and dark trousers, socks and no shoes. I sat on the other sofa to her side and at some distance so as not to invade her space. I chatted to her a bit but there were also silences.... Marilyn rocked, glancing in my direction periodically. She makes stereotypical gestures which it would be easier to draw than try to explain in words. This is the sequence from memory. She raises her left arm right up straight above her head, pushing the sleeve of her jumper up at the elbow. Then I think she touches that armpit with the other hand. She then holds the hand she has raised up at a distance directly in front of her face, palm to the face and brings it right in up to her face while vocalising loudly. In between she moves the fingers of both hands, but not in the same pattern. She bends down the little finger and the thumb for example and flutters the fingers in between. She

constantly grinds her teeth and the noise is loud and noticeable (F/notes 4/1).

At first I tried to talk to her in words and it was only when I became more attuned to her way of being and let her guide the communication that I felt, rightly or not, that I had at least demonstrated a wish to communicate with her. I did this by taking the risk of imitating her gestures back to her.

The carer had recently been in hospital for two months and Marilyn had visited. They had - and she demonstrated finger twiddling- i.e.. chatted for a bit. ..So, laughing, I tried ham fistedly to attempt to do one of Marilyn's movements. (I find it impossible to copy things like that so I knew I couldn't get it right.) It was as if a light had gone on. She suddenly looked at me with much deeper engagement and for longer - definitely I had given her a sign (F/notes 4/1, p. 2).

A little later I let her 'guide' me round her room and, although I could not be certain, I felt as though she was appreciating that I was trying to take an interest in her.

We then went to find Marilyn again and she now brought me upstairs to her bedroom - that is she came up, I followed and when she went inside I asked if I could come in and then did so.

We spent a good time in there alone together (more than half an hour). Marilyn was mostly not performing her movements (or did I forget them) and was looking around constantly (she had done that downstairs too). I could not say with any degree of confidence whether it was the case that she was 'showing' me round her bedroom but that is how I behaved and I could construe her meaning that way. Of course I realise that that was my meaning and it may not have been hers. It was clear that she liked her room and it felt to me as if she liked to have me in it but ...

I went round the room touching things and exclaiming and speaking. She was definitely aware of the fact that I was there. She had a faint smile and sometimes it was as if she got my meaning ...I do not know if this might be the case or whether it is impossible...Perhaps she is translating things other than words...

The carer who took me up to her room the first time had told me that very recently Marilyn had been to a music workshop and had really got a lot out of it. At one point when Marilyn was by the door her fingers made a sound that had a bit of a rhythm in it and I immediately clapped the rhythm back to her and it was as if she tried to copy a couple of times. Later when she tapped/or maybe just knocked against the door frame I tried again by myself banging on the chest of drawers but this time there was no response....

When she sat on the floor I did the same a little way off. I think I had been interpreting things correctly because she touched me a couple of

times - sort of tapping me by flinging her arms in my direction (F/notes 4/1, pp. 3-4).

Meeting Marilyn one-to-one encouraged me to try and relate to her and find different ways to communicate with her. I felt that a social encounter could take place between us, even if we could neither of us decode the content of specific acts. My fieldnotes indicate some awareness of the risk of over-interpretation in trying to 'read' Marilyn's behaviour. So, whilst very careful attention to Marilyn was essential to try and decipher her meanings, I learnt from her that my wish to wring specific meanings from the situation could be an obstacle. Though I was unaware of it at the time, starting with the person, taking their lead and sharing attention are all principles of the approach of Intensive Interaction which seeks to value the person and promote their social engagement (Nind and Kellett, 2002).

3.2. When realities are disputed

Communication issues were much wider than the question of how to communicate with people who did not use words. There were a number of situations where the person's reality and mine did not easily connect. Ruth was an older woman from a large Irish family who lived in a group home. Ruth was sight impaired, but this was far from all-determining. For example, she replaced the tape in my tape recorder the right way round when I put it in incorrectly. However, although I was able to spend time with her, I was frustrated by my inability to interview her. She kept up a series of conversations (which I called 'dialogues') which appeared to be an inner stream of consciousness, rather than participation in the interview. On the tapes it was so hard to pick up what she was saying that I was not able fully to transcribe them.

Though I was dismissive of these dialogues at the time, feeling that only once or twice did she 'really' answer my questions, there was a point in our second meeting where she seemed to use these deliberately to mimic the way that I was

asking her questions. My fieldnotes on this session suggest that I saw her communication as cutting across my duty to get information from her.

Certainly true of this occasion that Ruth did pick me up better and answer one or two questions absolutely straight. A lot of the second part of the time she did spend in her wee dialogues and although I tried to break into them I didn't succeed except occasionally... So, though I couldn't keep asking her questions and there was a point in the interview when I think she was kind of mimicking me asking questions, her dialogue was about that, it was a very comfortable time, although part of the time I just sat there while she did her wee dialogues (F/notes 5/2, pp. 2-3).

Yet the transcript of the session suggests that even in this unpropitious environment Ruth was able to use her chosen medium to incorporate my questioning into her world of meaning, thus equalising our positions in how the encounter was framed.

[Person speaks as if voicing an interior conversation/monologue - perhaps as if parent talking to her - 'what are you doing? You can't go in there' etc., 'C'm here' Uses other voices, whispers some of it.]

Lisa: And you go to church?

Ruth: Do you to church? Do you go to..? Do you go to brownies? Do you go to grandad's? [Whispered answers], Do you to ... etc etc. Do you go ...No

[Then she is asking questions] Do you go with Marie? Do you go with her?... (Transcript 5/2, p.1).

Ruth's mimicry, it seems to me, was effective in demonstrating that my 'wee dialogues' could be equally irrelevant to someone else as I seemed to feel hers were to me. She dramatised for me, not unkindly, the tensions in our attempts to meet each other. With hindsight, it seems to me that, rather than cutting across Ruth's dialogues, it would have been a more fruitful strategy to accept them and work with them. Taking a less task-oriented focus might not have yielded different information, but it would have demonstrated to Ruth that I at least acknowledged her main focus of concern.

A different example illustrates how a lack of shared social and cultural reference points with the researcher could create a barrier for research participants. Phil, a young man awaiting discharge from the locked ward of a long-stay hospital was hearing impaired and communicated through sign language. Since I do not sign we had to communicate indirectly and his signer (Pete) translated my questions.

At the beginning of the session I had congratulated myself that, despite the communication difficulties, we were all working towards the same end.

While Pete signed, he said out loud what he was signing, so I knew what was going on. I addressed my questions, obviously, looking at Phil, and then Pete signed them. I mean we worked as a team really (F/notes 15/1 p. 1).

However increasingly the signer sought to shape the interview in order to explain to Phil what he could expect life in the community to be like. At one point Phil dramatically interrupted proceedings:

So Pete said, we used to go to the swimming pool in the hospital often before but its finished now, its closed down, and in the new area there'll be a different swimming pool, shops and different people, and Phil was off on his own track. He wrote "Jaws" on the paper and so Pete said to him, "What's Jaws?" and he said, "It's a video" and then he pointed, he wrote "shark" on his paper and he pointed at his T-shirt, which I hadn't noticed, and indeed the T-shirt had on it a picture of a shark and some sort of nasty blood and it had the words "Shark Attack" on the T-shirt, and Pete said that he's interested, when he first knew him, he was very interested in strong predators, sharks and gorillas, powerful predators. Then Phil wrote on the paper "IRA die" (F/notes 15/2, pp.3-4).

Phil had staged a deliberate disruption of the performance that Pete and I were attempting to stage. By showing me a quite different side to what preoccupied him, Phil unsettled my assumption that I understood what was happening. A male interviewer or someone who shared his interests in video and football might have earned his respect more readily and been better able to pick up on his references. As it was, the session seemed not to be connecting with his reality. Was Phil pointing out to me that, although I had apparently circumvented my inability to use his language, I had not come close to understanding his meaning? The lesson I draw is that I had too easily assumed that my perspective was a shared one.

3.3. When speech is indistinct

In the above example, questions of gender and culture were a probable barrier to communication and understanding. When I first met Sheila, an older woman,

it was easier to find things to talk about, such as clothes, but my problems in following her speech and accent caused me to miss a lot of what she was saying. Sheila also lived in the long-stay hospital and was expecting to be discharged soon, but after five previous failed placements she and the staff had fears about how things would turn out. Visual and other clues helped me to follow more of what she was saying. Later she took me on a tour of the hospital which meant that I was able to see some of the things she was talking about and meet some of the people important to her. Despite any problems I might have had in making out her speech, Sheila was quick to tell me what I wanted to know about her life. Within the first few minutes of meeting her she had told me what she most wanted, what mattered to her (friends and income) and what she did every day.

Lisa: What I'm interested in, Sheila, is the problems you had getting a home of your own and how you feel about that really.

Sheila: I want it, I want them, housing, own house.

Lisa: Do you think things will be better in the new house?

Sheila: Aye.

Lisa: So you've a care manager. And do you think she gets things sorted?

Sheila: Sorted the now, to be out, my own room, my own kitchen ...

Lisa: Oh right, sounds nice, great, right. So what are the important things I should know about you, Sheila? Tell me about you.

Sheila: I ?? good pals, my pals.

Lisa: So you've got lots of pals.

Sheila: Aye, I've got pals, I've got pals, pals.

Lisa: Right.

Sheila: See my pals, have a cup of tea and a biscuit, see my pal see my pal, cup of tea... (Transcript 12/1, pp. 1-2).

Sheila was a gatherer of news and gave me the latest update from her daily trips round the hospital. For example, on one occasion, when the paper was open at the job vacancy page on the table in the staff room where we met, our conversation went as follows:

Lisa: A lot of the hospital is closed now.

Sheila: I know, [part of hospital] shut down, shut down.

Lisa: Gosh.

Sheila: Last week.

Lisa: Oh really.

Sheila: Aye, the carpets all away...

Lisa: Are the staff worried? Are they worried about their jobs?

Sheila: All worried about jobs, More got told about it.

Lisa: There's a lot of people affected.

Sheila: Aye [name], he's away to his new house (Transcript 12/2, p. 7).

Sheila's valuable contribution could easily be lost. By offering suggestive comments and prompts I was sometimes able to elicit more detailed information, a contrast with the approach that seemed to work with Mairi, where I needed to wait for her to verbalise her thoughts. I also found the tape recorder useful because it was sometimes possible on repeated hearings to pick up things that I had not heard the first time and a local transcriber was able to record some phrases that I had missed. In working with Sheila I needed to give very careful attention to her speech, but also to supplement these interactions with other activities, such as visits.

A one-to-one interview could be too pressurising or boring for some people. In particular my technique was not effective with Colin, a young man labelled with challenging behaviour who had moved into the community. In response to my questions he replied that he did not know what to say. When he did speak I had difficulties hearing all his words and according to his support worker this was because his teeth did not fit properly. Being a gadget lover, he focused on my tape recorder. He could not distinguish it from his Walkman which was broken, but which he switched on in an attempt to get it to record. This subverted his role as an interviewee since he spent much of the time with his headphones on and his Walkman playing into my tape. In any event I did not succeed in enabling him to express who he was or what he had experienced. It is possible that I should have paid more attention to how he managed his sensory environment and that he was trying to shut out my intrusion or his actions may have demonstrated that he was trying to work out the rules of the game and to play it.

Interpreting speech included a mixture of social, cultural and material issues. For example, when I had problems 'hearing' Sheila this could have been because her accent was unfamiliar to me, because she had not been listened to sufficiently during her long residence in an institution to make it worth her while to speak clearly, because she had physical problems in forming words or because she had not had access to speech and language therapy. Therefore with some people who used speech I should have been just as alert to considering

alternative ways of reinforcing communication, using contextual clues and adapting my way of asking questions.

3.4. When non-verbals mislead

Non-verbal signs were not more self-evident than communication involving speech. For example, although Michael expressed himself primarily through his physical presence, it was possible to misread the signs of Michael's body. His mother explained that an apparent smile could be a grimace, indicating a fit, and she recounted a story of a worker who continued to misinterpret this as happiness. Stew, his worker, said something similar. Michael's parents could see and interpret his grimaces as a fit, but others might miss them. It was not possible even for his parents to know for certain how much Michael apprehended. His mother felt that he did recognise close family members, but she had no way of knowing, for example, whether he missed her mother who had recently died, or whether he realised that she was no longer there. She summed up the risk of being misled by appearances when she said, 'you need to look beyond what you see' (Transcript 8/4, p.10).

Similarly, it was not necessarily the case that using a non word-based technique, such as drawing, provided a medium that would make it easier for the person to express themselves. When I met Anne in the day centre and we talked about her house I suggested that we drew it on the assumption that this would make the question more interesting and accessible for her and would act as a trigger for discussion. But Anne put the drawing in her folder and promised to colour it in at home. She assimilated the exercise to one she was familiar with and did not see it as an opportunity to express something about her own situation.

These two examples illustrate that assumptions about communication need to be tested. Appearances are no easier to read than words and equally it is a false assumption that using a picture is more instantly recognisable as a cue than explaining something in words.

3.5. Learning from the research experience

In this section on communication I have emphasised issues of interpretation of meaning as well as of eliciting responses. Alternative means of communication were no less amenable to naive interpretation than speech and moments of miscommunication highlighted the problematic nature of trying to understand the subjectivity of any other person.

There were benefits to me as a researcher in being challenged to adapt my communication style to that of the research participants. I became more aware of the risk of assuming that meanings were shared and of imposing my own communication style. In particular I realised that I had brought the experience of a qualitative researcher who was at ease with open-ended interactions and word-based interviews into environments where these approaches were likely to be ineffective with, or disadvantage my communication partners. However the lessons that I learned for my everyday research practice were in many respects extensions of good qualitative interviewing techniques and included following the person's lead, paying attention to small clues and being sensitive to the social aspects of the encounter from the other person's perspective. In a review of the literature Lloyd, Gatherer and Kalsy (2006) suggest it is imperative that researchers respond to the challenge to include people with expressive language difficulties in qualitative research interviews, both to gain greater insight into their perspectives and to counter discrimination. I found that there was no one communication technique that would have been appropriate for all the research participants and that it was important to be bold and try out a range of approaches. I needed to be willing to hear information in unexpected ways and at unpredictable moments in order to pick up and respond to the clues that were offered.

Communication issues and ways of tackling them emerged in interaction. The issues were not simply located in the research participant, nor could they be read off straightforwardly from their impairments. Communication had to be

negotiated between us and my own technical, social, cultural and material capacities were equally at issue. Although the environment of a one-to-one session in which I made it a priority to build a relationship with the person did not suit everyone, it provided the most opportunities to enable me to be attentive to the person's preferred communication and to be guided by them as to the best method to work with them. However a much longer-term relationship would have been needed to communicate well with someone with profound learning disability or to negotiate their symbolic meanings (Klotz, 2004). The possibility of a researcher being able to communicate may depend on whether there has been pre-existing work over many years to build up and interpret the person's communication.

In this study I was very aware of the embodied nature of communication, which was mediated through bodily practices of seeing, hearing, gesturing, touching, laughing and speech production. I would identify the quality of attentiveness to the other person as that which might create the best physical and social environment for effective understanding. In many ways the issues that I have identified are merely examples of problems of interpretation that are inherent in any communication event or research situation. However it has been important to note the dynamics that were at work because people with learning disabilities, especially those with severe cognitive or communication impairment effects, have often been excluded from research studies. Corker made the case that early versions of the social model of disability gave insufficient attention to exclusion through language and communication (Corker, 1998). The research process served only to highlight that, whether or not they used words, the communication of these participants was easily ignored or misunderstood. Research practices therefore should systematically seek to redress this disadvantage.

4. Acts of resistance

In this section I want to illustrate circumstances in which the people in this study found opportunities to subvert the labels that they had been given, to refute the

meanings that I or others seemed to be making of their situations and so to assert control over their own story. In so doing I consider that they demonstrated agency as active research participants. The examples I give are refuting assertions by others, countering a negative reputation and refusing to 'perform' to order. Some of the examples I have already given in other sections could also be interpreted as including elements of resistance or defiance.

Tracey was receiving one-to-one support in a specialist day centre because she was considered vulnerable. She had been diagnosed with a severe and enduring mental health problem. Yet Tracey sometimes overthrew the assumptions of incapacity made about her. For example, in an art group session, Tracey's new support worker put the brush into Tracey's right hand and after some moments commented that her painting appeared clumsy. 'That's because I'm left handed!' came Tracey's quick response (F/notes 7/6). Mairi was selected for the study because she was experiencing a newer form of day opportunities as an alternative to full-time attendance at the day centre. For two days a week she had individual support to take part in activities in the community. Mairi made it clear that she disputed the account given by her current support worker in the outreach project that she had not done such interesting things when she had attended the day centre on a full-time basis.

Mairi: We used to go places when we were at Hillview.

Lisa: Right.

Mairi: We used to go out (pause) out places.

Lisa: Oh right, okay.

Mairi: When we were at Hillview.

Lisa: So you weren't always stuck in the centre.

Mairi: Right, something different.

Mairi: We used to have days out.

Lisa: Mm hm. Right. Very good.

Mairi: When we were at Hillview.

Lisa: Right.

Mairi: We got days out.

Lisa: Sounds good (pause).

Mairi: Days out.

Lisa: Were they quite good? Yep (pause).

Mairi: em and at Hillview. (long pause) Having concerts. (pause) concerts at one time and then em. (pause) We used to, we all sang.

Lisa: Right. Do you like singing? (pause) Mm.

Mairi: We all miss that. (Transcript 11/2, p. 7).

Mairi was providing an alternative view on how she and her peers had experienced day services. She was letting me know information about the day centre that had been suppressed or glossed over in the worker's account, and she was giving me access to the feelings that she and, as she believed, other people who used to attend the day centre had, about what they had lost. It was not the case, she claimed, that they had never gone out from the day centre and she had enjoyed the communal experience of being in a choir with the other people from Hillview. It seemed that Mairi viewed the change to individual support and outreach programmes with some ambivalence.

Refutations could be by acts as well as by words. At my first meeting with him Rob confounded the negative reputation that had preceded him. His key worker at the day centre had set up a meeting for me there with two of the workers who supported him in his tenancy. For about three quarters of an hour they talked to me about his history and the risks that he could pose to others. It was agreed that we would walk casually into the day centre during the session when people were having tea and see if we could 'happen' across him. In fact we met him straight away in the corridor and he came through with us, got us coffee and sat with us, much to the workers' surprise.

Refusal to participate may be the only option for someone without power. Margaret, one of the three young women with profound and multiple impairments gave a very clear demonstration that she would not 'perform' to order for the purposes of the research, when she refused to demonstrate a skill on demand. While some of us played wheelchair rounders in the sports hall, a student was working with Margaret on using the Able Net equipment. If Margaret extended her arm to press a red button it switched on a music player. When I came over her key worker tried to make her repeat the exercise to show me what she could do. She did not respond. Then the sports worker, a significant person in her life came over and asked for music. Margaret put the music on and the key worker interpreted this exercise of choice as a deliberate attempt to show her up, exclaiming to Margaret 'you're at it!' (F/note 2/3, p.1).

Margaret had an existing and important relationship with the Disability Sports Worker and a genuine liking for the music on her player; she rightly rejected the attempt to manipulate her capacity to exercise choice. I understand this incident to be about autonomy and embodiment. The purpose of training Margaret to use this particular piece of technology was to extend her physical capabilities and to enable her to exercise choice and have greater independence. She resisted when it was used differently, to control why and when she should press the button. Her body, augmented by technology, was to be the site for greater independence and she had learned her lesson well, also using it for resistance. For me these events rewrote the image I had of Margaret's body; hitherto I had seen it as fragile but the new observation that she could control one of her arms made me see it and thus her as more powerful with more possibilities for control than I had thought open to her.

A variety of opportunities enabled the research participants to create alternative narratives. Thus Mairi's objection to the support worker's story that she had had fewer opportunities at the day centre was made possible by all of three steps that led up to her different version of events: the opportunity for her to hear what the worker was saying about her life; the steps I took to check out the account and her having the chance to comment privately. The equipment provided to Margaret enabled her to exercise choices. In these few examples the participants challenged a number of potent myths including incompetence (Tracey), a negative reputation (Rob), the inevitability of progress (Mairi) and that people with learning disabilities are likely to comply with suggestions (Margaret).

5. Conclusion: Recognition

In this chapter I have told a number of interlocking stories and I will now seek to draw together their implications for constituting a research account of people who live with the designation of 'high support needs'. One thread of my argument is that some people can be marginalised, even within the category of

Learning Disability, because their incapacity is seen to challenge the paradigm that everyone with learning disabilities can learn and contribute. Viewed as a social practice, research can reinforce this marginalisation by systematically reproducing the incapacity of some people to make meaning, 'speak' their mind and therefore influence their social reality. My research experience has highlighted some of the methods that can increase participation including: prioritising the person's subjectivity rather than the researcher's task; using a range of communication methods; making space to develop a relationship and allowing time for this; being alert to small signs that may convey meaning; and, not excluding the possible contribution of intermediaries. I found that the person themselves was often the best guide as to how to communicate with them; that I had to learn to live with some uncertainty about intentions and meanings; that taking a risk and trying something could pay off; and, that research participants, as much as the researcher, might use opportunities that presented themselves as possibilities to demonstrate their point.

I would contend that the experiences of research with people with severe communicative and cognitive impairments provide a challenge for emancipatory research practice. A model based on enabling greater control by disabled people through research practices that assume cognitive understanding and the capacity to engage with all stages of the research process is not inclusive enough. There are some people for whom 'easy Read' information is not sufficient to make the research process accessible. Emancipatory practice must embrace a readiness to accept contributions that may be partial and mediated through the interpretations of others, but nonetheless significant. At the end of the previous chapter I explained that I identified with Young's contention (1990) that social justice claims are not theoretical but are claims made by some people upon others. In this research the claims made upon me were social, emotional and political, as well as technical. Stanley notes: 'When the story includes injustice and oppression, the listener is implicated and called to take up the baton of remembrance' (Stanley, 2002). Thus listening can become an act of solidarity.

A further and related issue raised by this chapter is the epistemological and methodological appropriateness of research paradigms that emphasise the analysis of talk. There is a danger that those who seem least likely to be producers of reflexive identities through dialogue could be seen as beyond the reach of analysis and not part of the conversation. However ‘talk’ need not be confined to speech acts and I have suggested, as do Lloyd, Gatherer and Kalsy (Lloyd et al., 2006), that it may be particularly appropriate to approach the identities of people who experience cultural exclusion through their social interactions.

The mutual attempts at communication I have described, with their gaps and false starts, give me some sense of the idea of shared vulnerability which, according to Turner, can provide the grounds for according respect to others and thus is foundational for human rights. Vulnerability assumes the possibility of reciprocal sympathy. This emotional response is only possible, though, because an act of recognition precedes it (Turner, 2006). Recognition refers to a mutual awareness of commonality and it does not mean that differences are wiped out, but that solidarity is possible while acknowledging difference. Empathy is therefore not sufficient in overcoming dualisms and stimulating social action, and I agree with French and Swain that ‘listening is not enough’ (French and Swain, 2004) unless it leads to changes in practice and to increased participation and control by disabled people. Enlarging research practice to be inclusive of a wider range of modes of cognition, subjectivity and communication may be a modest step in that direction.

CHAPTER FIVE Interpreting Needs and Claiming Resources

1. Introduction

In this chapter I explore the nature of 'high support needs'. I consider in turn its uses as an administrative category, its emergence as a political claim, symbolising tensions over the distribution of resources, and its consequences for the individuals so designated.

The heterogeneous category of people with 'high support needs' or 'complex needs' has emerged to embrace those who do not easily fit within the single label of 'Learning Disability'. Naming or 'labeling' and representation pose interconnected political, theoretical and praxis issues in Learning Disability research (Brown and Smith, 1992, Priestley, 1998, Rapley and Ridgeway, 1998). In this Chapter I want first to examine the unstable category of 'high support needs' as a problem of distribution. Here I draw on Stone's (1984) work on the uses of Disability as a formal administrative category. Stone examines the category of 'Disability' as a means of resource distribution that is used to filter those who can be exempt from responsibility to contribute through employment, from those whose needs are not recognised as legitimate reasons for exemption and the receipt of welfare. In Stone's analysis, such categories determine rights and privileges and the study of them highlights 'why social institutions respond to some individuals differently than to others' (Stone, 1984:49). I will ask what the emergence of a category of 'high support needs' (a justification for additional support) reveals about normative conceptions of reasons for funding support for people with learning disabilities.

The issues raised by the experiences of individuals in these case studies can be seen as part of wider debates about how to achieve social justice. The 'redistribution or recognition' question (Fraser and Honneth, 2003) characterises two perspectives on justice: the redistributive paradigm, which emphasises

economic restructuring as the remedy for injustice; or recognition, which emphasises cultural change to revalue the identities of marginalised groups (Fraser and Honneth, 2003:13). Reconceptualisations of the concept of 'care' (Williams, 2001, Fine and Glendinning, 2005) illustrate how recognition can be relevant to debates about how best to achieve justice in social care (Watson et al., 2004). According to Williams (2001:487), care should be seen as an issue of public and mutual responsibility within an interdependent concept of citizenship. According to this perspective, both cared and cared for should be enabled to develop their capabilities and manage their dependencies (Fine and Glendinning, 2005:162). Thus dependency is seen as a shared characteristic, rather than as a marker of difference or an occasion for the exercise of power over others. The ways in which particular needs for care are construed as indicators of dependency, rather than as opportunities to develop capacity, is a theme of this Chapter. Without support to participate, and to have their needs represented, people deemed to require high levels of support will not be included in citizenship.

Fraser (1989) has pointed out the importance of struggles over needs as part of contemporary political debate. The area that she highlights for enquiry is not how needs are satisfied, but the ways in which needs are contested through discourses about the interpretation of needs, which she calls 'needs talk'. 'Needs talk' is thus effectively one medium through which debates about inequalities are played out and a key site for examining competing claims to social citizenship. 'High support needs' could be seen as an example of what she terms 'runaway' or 'excess' needs that escape the private sphere and become the concern of the state (1989: 109). She identifies three stages in such struggles over needs claims: the attempt to legitimate a new need as a public concern; the attempt to validate or invalidate it; and then the debate over whether it should be satisfied. She is therefore concerned with the process by which needs are claimed, legitimated or opposed, and considered as the state's responsibility to satisfy. I thus approach the question of needs from the perspective that needs represent claims to resources. The taxonomy of needs developed by Bradshaw (1972) recognised that needs become interpreted in relation to the responses that can be made, hence his categorisation of needs as normative (determined by a standard criterion), comparative (compared with

others not in need), felt (from the perspective of the people who experience the need), and expressed (stated explicitly by those with needs). Further, the concept of a 'claim', following Fraser, implies a political debate over legitimacy, and I will look at how different needs claims fared differently in terms of the acknowledgement they received. I will consider some examples where needs claims were contested and I will argue that these may indicate that there is reluctance to accept that some needs are a public, rather than a private responsibility to satisfy.

Recognition of difference also implies that justice may require differential solutions; however these differential claims are based on an appeal to universal rights. Morris (2001:11) makes these points unambiguously when she argues that: a) society's response to difference creates inequalities for disabled people; b) at its most extreme this is part of a denial of disabled people's right to exist; and c) recognition of their claims to equality should lead to entitlements to different treatment in order to access rights. She writes:

Up until now, the recognition of our difference has been the gateway to a denial of human and civil rights: to be recognised as "severely disabled", for example, all too often leads to segregation in an institutional setting. We need to change this situation so that the recognition of our difference becomes the gateway to the provision of what we require in order to access our human and civil rights. We have to recognise that disabled people will not get access to full human and civil rights by being treated the same as non-disabled people (Morris, 2001:12).

A human rights framework is increasingly advocated as the most robust basis for challenging discrimination against people with learning disabilities. In its response to the Joint Committee on Human Rights report on the human rights of adults with learning disabilities, 'A life like any other?', the Equality and Human Rights Commission (EHRC) proposes that the principles of human rights, 'fairness respect, equality and dignity' need to be embedded as part of a 'human rights culture' in public services in order to achieve greater equality for people with learning disabilities:

We believe that greater integration can be achieved between promoting human rights and promoting equality in ways which strengthen outcomes in relation to both - for example, human rights principles providing the necessary underpinning for the successful

delivery of equality duties (Equality and Human Rights Commission (EHRC), 2008:2).

The appeal to universal rights is part of an effort to overcome the inequalities experienced by people with learning disabilities by asserting their claim to be treated with respect; it is therefore an example of recognition. The principles articulated are echoed by the writers discussed above who propose an 'ethic of care' which values mutualism, and recognises the importance of caring work as an alternative to a social strategy based purely on work-based productivity (Williams, 2001, Morris, 2001). Gilligan (1982) was the first to distinguish an ethic of respect, responsiveness and dignity, rooted in experience and interconnectedness, from an ethic of justice based in the rights of the autonomous individual. Later writers have sought to decouple the responsibilities of caring from the role of women, and have critiqued the sharp antithesis drawn by Gilligan between caring and autonomy, but have continued to develop the principles of an 'ethic of care', which include fairness, interdependence, mutual responsibility and respect and attentiveness, as integral to citizenship (Tronto, 1993, Sevenhuijsen, 1998, Kittay, 1999b, Sevenhuijsen, 2000). These principles may serve as a template against which to assess the responses of services to needs claims.

In this chapter therefore I will also consider the experiences of service provision and how these follow on from the way that needs were assessed and responded to. This leads me to consider the constraints that were affecting service provision and the consequences for the experiences of individuals. The social model of disability highlights how social barriers to participation create disablement (Oliver, 1992, Swain et al., 2004), and disabled feminists have particularly emphasised the importance of understanding how personal experiences have been shaped by the denial of opportunities (Morris, 2001, Crow, 1996). Fraser (in Fraser and Honneth, 2003) points out that needs statements are always in the implicit form 'in order to ...'. I will examine the consequences of the variable responses to the legitimacy of different needs claims for the provision of services. My focus in this study was on the relationship between high support needs and a particular outcome, the individual's experiences of exclusion and inclusion and I shall therefore comment

throughout on the implications of the way that needs were accepted (or not) and satisfied (or not) for the person's experiences of inclusion.

The organisation of this chapter is as follows. I begin by considering in Section 2 the uses and meanings of the category of 'high support needs' as it was presented to me when I began to identify people to take part in this research. In Section 3 I describe the reasons that individuals in this study were deemed to require levels of support that exceeded the norm, and I also consider the consequences for individuals when their needs were not met. I will argue that competing claims can be discerned, principally as a discourse of protection and a discourse of inclusion. In Section 4 I look at instances where claims were contested, and I present two case studies where there were struggles to establish the case for resources to be allocated. I argue that these examples indicate assumptions about responsibilities for care. I conclude in Section 5 by arguing that the needs claims most likely to be neglected in this group were those that form the basis for participatory citizenship, such as support for communication, and that recognition of their rights to be treated with respect is essential to achieving fairness.

2. High support needs as an administrative category

The act of identifying a population to study highlighted the problematic features of attempting to define a category based on needs and also provided indications of why the designation of 'high support needs' might have uses for those administering service systems.

Conversations that I had with service commissioners and service providers in the course of setting up this study, emphasised that 'high support needs' was an unstable category which included a range of people who presented a challenge to ordinary forms or levels of service provision. For example, the day centres, which I also approached for research subjects, were providing services for

people who had traditionally received support in the community, but their managers expressed tensions with the terminology in use and revealed issues in stretching definitions to accommodate needs. In the case of day centres higher staff ratios were still principally based on the need for high levels of personal care or supervision which would determine someone being placed in a 'complex needs unit' within the centre. One manager explicitly recognised that a recent change in terminology had not fundamentally altered a resource allocation system that prioritised high levels of physical dependency.

The politically correct phrase for people with more high dependency needs is "high support needs". Unless it has changed - social work spend ages deciding what we should call people and then don't tell people (F/notes MD/1, p. 1).

According to this manager, people with high support needs by this definition would include people with sensory impairment, wheelchair users, people with mobility aids, people with challenging behaviour, people with communication needs, people with epilepsy and people with physical disability and profound impairment. However there was awareness of other emergent needs claims. The manager of another centre noted the existence of people in the day centre who did not meet the criteria for the complex needs unit, but nonetheless required additional support. He estimated that out of 80 'students', 17 were in the complex needs unit, but there were 21-25 people altogether in the centre with 'high support needs' and these others were 'very difficult to pigeon hole'. They could include, for example, 'people with mild learning disability and challenging behaviour' (F/notes, M2, p. 2). Thus in practice the definition of complexity was wider than severity of physical or mental impairment.

'High support needs' also included situations where a person's behaviour or mental health (dual diagnosis) was considered potentially problematic for their life in the community. The hospital discharge programme was also encountering a diversity of needs within the same category. The member of the project team responsible for the discharge programme from a long-stay hospital told me (July 1999) that high levels of impairment were only part of the reason for high levels of support being commissioned in the community and he also acknowledged that the recognition of need was relative and subjective:

It would also include a rather different group, people who had complexities of behaviour or dual diagnosis and he pointed out that this was a slightly shifting category, depending on their environment and who was assessing them (F/notes, CT/1, p. 1).

Distinctions between those who did and did not qualify for inclusion in this category were fluid, because the nature of the challenge that an individual posed might be viewed differently by different assessors or might be more manageable in some situations than others. Thus 'high support needs', at least at the boundary, was not so much a property of the individuals so designated, as a function of the support and service system set up to manage their needs and behaviour. From a Foucauldian perspective, it can be seen as forming part of a system of differentiation (Foucault, 1982) which brings them within the scope of attention by care and support services.

Therefore right at the beginning of the study I encountered a number of paradoxes in the categorisation of people as having 'high support needs'. These included: that the category was both heterogeneous and malleable - it could be used to embrace anyone who did not easily fit the model of service provision on offer; that some of the people included were very difficult to describe in terms of any specific impairment category; that physical, sensory or mental health needs rather than learning disability might be determining the need for service; and that a high level of need was not necessarily consistently matched by a corresponding entitlement to services. Despite a recent change in language, intended to emphasise need rather than dependency, managers described people in terms of impairment and dependency categories. There were also indications that the dependency-based models of needs assessment and resource allocation were breaking down. Both in the day centres and the hospital discharge programme, needs for extra support that were additional to needs for physical care, principally represented by people with mental health problems and challenging behaviour, were increasingly claiming the attention of those responsible for services. Stone (1984) has analysed the development of Disability as a legal and administrative category designed to determine who should have access to aid from the State. She argues that, despite the origin of the category of Disability as a means to limit needs-based distribution and the

invocation of medical authority to legitimate definitions and claims, it is politically created and subject to pressures for expansion. The category of 'high support needs' seems similarly to make sense only in the context of competition for resources and to designate a case for additional support rather than to describe a coherent category of persons. However the vagueness and ambiguity that characterise it may therefore increase its usefulness as a political category, while at the same time making it a weak basis for entitlement.

Marginality is another characteristic of the category described. The descriptions provided suggest that the very different sorts of people encompassed by the definition share a contingent position on the edge of mainstream services. Just as their needs are difficult to fit into any existing category ('difficult to pigeon hole') so there is ambivalence about where and how they should best receive a service, and indeed, who amongst them should have a claim to additional support ('a slightly shifting category'). This very marginality makes the category a useful subject for an enquiry because the characteristics that are ascribed to those at the margins can reveal the norms and preoccupations of the mainstream. In this case the existence of the category of 'high support needs' might indicate that significant mental and physical health needs, sensory impairments and behavioural problems, are not easily embraced as mainstream concerns for social care Learning Disability services. This may relate to the previous history of the responsibilities of health and social care, an issue to which I shall return. At this point I am concerned more with the implication of such designations as representations and as instruments of power relations.

In discussing representations of physical disability, Garland Thomson (Garland Thomson, 1997) has shown how bodily differences can be constructed within social power relations to attribute physical deviance to some and thus reinforce dominant normative images, such as the healthy, autonomous ideal of liberal American culture. Similarly it is appropriate to ask what norm is being reinforced by marking out people with profound impairments, sensory impairments, mental health needs and challenging behaviour from the mainstream of people with learning disabilities who require support in the

community. One answer might be that these needs disrupt the aspiration for a governable population of people with learning disabilities whose needs can be integrated and who can learn to adopt productive roles within mainstream society. People whose impairment is severe may also disrupt any assumption that the requirement for support will diminish over time and with appropriate adaptive measures. Thus 'high support needs' as a category may function both to regulate the level of resources 'normally' required to support people with learning disabilities in the community, and to reinforce the proposition that most people with learning disabilities can be integrated into mainstream community living.

3. Claims for high levels of support

Having considered how the category of 'high support needs' was defined administratively I will now look at the reasons why different individuals were considered to have needs that required a high level of support. Interpretations of needs were voiced by managers, key workers and support workers; family carers (parents and siblings) and people who commissioned services. The data sources I have drawn on for these accounts include interviews, observations and, in some instances, case records, including assessments which I was given access to for some people when they were relevant to a particular case study.

The main justifications for high levels of support identified in the case studies were:

- care because of profound impairment and complex health needs;
- support and supervision because of behaviour that challenged, vulnerability or risk to others; and,
- support to teach independent living skills and promote social inclusion.

The categories of needs (severity of impairment, risk/safety and promoting independent living) were not necessarily independent of each other, as I shall show.

3.1. Care

A discourse of care was used to justify intensive or additional support for people with complex physical or health needs. In the case of people with profound impairment (Michael, Jennifer and Margaret) physical care needs and complex health needs were prominent in the requirement for additional support. Jennifer and Margaret were in the 'special needs' unit at the day centre because of their complex care needs; their profound impairment and associated health conditions created a lack of independence in any aspect of self care (washing, toileting, feeding) and that was seen to determine their need for additional support, in the form of an increased staff ratio. For example, Jennifer's keyworker told me that Jennifer was put on a wedge every morning at the day centre to drain her chest and that she needed to be 'moved about' (F/notes 1/1, p. 1). Michael's extensive care needs were also the reason for him receiving support. However in his case the need to provide him with stimulation was recognised. The community nursing report completed when he was 18, as part of a resource application for adult day care, comments that 'his care requirements are vast' and details his 'profound mental handicap' (sic), need for assistance with all aspects of daily living, including continence, his epilepsy and periodic need to have rectal diazepam administered and regular enemas. From a nursing perspective, Michael was seen to need full-time support.

It is my opinion that in terms of day care, Michael requires to be placed on leaving school without break in continuity in the special care unit which can not only manage these problems but also provide an appropriately stimulating and varied environment in order to maximize his quality of life. Such a placement would require to be given on a full-time basis and escorted transport would be required (Community nursing report in F/notes, 8/6, p. 22).

In addition to physical needs, complex health needs, and particularly uncontrolled epilepsy, were significant reasons for which additional care was seen to be required. Ultimately Michael was to receive two-to-one support in the day centre because of his epilepsy, which could frequently result in the need for medical intervention. Margaret's mother also emphasised that Margaret's health needs were an important aspect of her life.

She also mentioned...that another area was health needs, what she called the medical side and medication, medication and doctoring she called it. Margaret has a lot of seizures. She takes chest infections because of sitting in the chair all the time and she has cold feet because of very poor circulation (F/notes 2/1, p. 8).

Whilst a need for assistance with all aspects of personal care and complex health needs was the justification for additional support based on care requirements (effectively an assessment of dependency), in practice there were limits to the public responsibilities for this care, however comprehensive the need. When the person lived with their family, primary responsibility for care was perceived to remain with them. Because Jennifer, like Margaret and Michael lived at home, the responsibility that local services took for her care was essentially to provide support during the day and regular respite for the family. Jennifer's mother considered this support very important, but pointed out that about the only chance her daughter, who was nearly thirty, had to go out in the evenings was to a local club that another mother had set up about a decade ago (F/notes 1/3, p. 1).

The senior social worker who assessed Michael for day care considered that part of the justification for five-day-a-week care was to provide his parents with a break; the underlying assumption was that they had primary responsibility for his lifelong care.

Michael requires continuity of care at a similar level to that which he is afforded at ... [name of school]. That is a day/daily placement providing him with a degree of supervision and stimulation which cannot be expected from his parents on 24 hour basis. This support respite that .. [name of day centre] might provide is as important to Michael's parents as it is to the lad himself as without it the family would be subject to considerable strain in providing continuous care (Resource centre application in F/notes, 8/6, p. 21).

This was still the view of his then social worker in 2000, some eight years after this assessment when I interviewed her about her role in Michael's life. She said that the social work input was 'light touch' and consisted mostly in the paperwork for the respite arrangements, unless there was a crisis (F/notes 8/7, p. 1). His mother confirmed that she 'doesn't really see much of social work' (F/notes 8/8, p. 3). Michael's social worker also said that Michael's health needs did not 'feature largely in reviews' (F/notes 8/7, p. 1) as his mother

coped with these on a daily basis. It was considered that his mother could administer the rectal diazepam and enemas, even though his care workers could not. At the day centre staff were only allowed to respond to severe fits by calling an ambulance, resulting in Michael having many visits to Accident and Emergency.

Margaret's health needs were also a reason for responsibility reverting to her mother and could constitute a reason for exclusion from service. When I visited her day centre I learned that Margaret was excluded from the centre during her frequent chest infections, a situation which paradoxically meant that she did not have access to physiotherapy services for her chest condition, as this was only available through the centre (F/notes 2/2, p. 1). When visiting the day centre at lunchtime to see Jennifer, I observed staff telephone Margaret's mother to take action when they thought she might have a chest infection (F/notes 1/2, p. 1).

Back in the unit we sat down to lunch. One of the workers was concerned about Margaret. She was in her chair at the table and the worker was trying to feed her, but she wasn't accepting food. A worker asked her if her throat was sore. She managed to look down it and it was very red and inflamed. She got a couple of others to confirm it. The speech therapist was called over - a bit reluctantly. It was decided to phone Margaret's mum and another worker did so (F/notes 1/2, p. 1).

This situation arose because of the group nature of the care setting which brought together people who were considered vulnerable to infection. Therefore, despite Margaret's identified health needs constituting a reason for the care package she received, the centre's responsibility for her was conditional on good health; when she had an infection, responsibility reverted to her mother.

Part of the explanation for health needs being viewed as beyond the responsibility of the day service, may have been the division of labour between health specialists with learning disability training and generic staff in the day centre. This is illustrated by an incident I witnessed concerning support for Jennifer. Choking would be one of the major risks for people with Jennifer's needs (Leslie et al., 2009) and in interviews day centre staff expressed their concern that having to 'clear her chest' was something that prevented her

further inclusion, and yet practices that should have protected her were not necessarily in use. One lunch time in her day centre I witnessed the frustration of a specialist worker (a speech and language therapist) who was showing Jennifer's new key worker how to feed her.

Meanwhile another visitor was sitting with Jennifer while her new key worker fed her. She introduced herself - speech therapist, from the CLDT (community learning disability team). The speech therapist looked directly into Jennifer's eyes and spoke to her. She supported Jennifer's head forward to help her cough, talked to her and sometimes fed her. Later I asked her about her input. Jennifer has a feeding programme (which she showed me) which is regularly monitored by the CLDT. Because the key worker is new she is here to offer support and show her, for example, head positioning. Jennifer was coughing and tried to cough in between. There was discussion about the best way to clear her chest. The speech therapist suggested that a suction tube could be used. Another member of staff said they would be willing, but could not do it until they had been trained. There was one in the cupboard she said, but no one had come to show them how to use it. The speech therapist demonstrated as close to exasperation as I guess she ever does. "I can't understand how you can have one and it can be left in a cupboard" (F/notes 1/2, p. 1).

It is not clear whether there had been a clear request for staff training which the specialist service had been unable to meet or whether the need for training had not formally been identified. However it seemed clear that the liaison between specialist health input and everyday social care practice in this setting was problematic.

An assessed need for additional support might relate to factors other than individual need. Notably, moving and handling regulations were a reason that higher staff ratios were required in the 'complex needs unit' of the day centre. Health and safety requirements said that equipment (hoists) should be used to move people and that two staff were required. In fact both Margaret and Anne were very slightly built and in practice staff had to manage as they could. I experienced the way that staff were stretched to find two people always to move someone. I was pressed into service to help move Margaret and I was told that the fact that Jennifer was so light was an advantage in enabling her to go out as one person could lift her, even though it was against the rules (F/notes 1/1, p. 4).

Limiting practices were therefore in operation where there was a lack of expertise or resources available, even when a person may have been assessed as requiring significant levels of additional care. I now want to consider whether a need for care itself created additional dependencies. For one young woman, dependence for self-care did lead to an unwarranted assumption of sensory impairment. When I met Jennifer's mother at her home she presented a very positive picture of her daughter as a young woman, while also being very clear about her impairments. She told me in detail about what her daughter took pleasure in, for example having a bubble bath and her hair washed. Jennifer also had severe impairments, as her mother explained; she had no speech, could not use her hands, required a wheelchair and experienced fits. However she could indicate choice and would close her eyes and turn away when she did not like something. What had been overlooked for many years in professional assessments of Jennifer was her capacity. Before the age of 19 professionals had considered that she also had no sight and she had attended a centre for the blind. Her mother described having to 'fight to get acceptance' that her daughter could see. She pointed out that Jennifer followed things with her eyes and looked towards the clock if it moved (F/notes 1/3, p. 1). This was confirmed by Jennifer's key worker at the day centre who felt that Jennifer could be included a lot more and said that she 'can hear and see' (F/notes 1/1, p. 4). Jennifer had therefore been disabled by the assumption of sensory impairment in addition to her considerable physical needs and this may have limited the positive support for her development as she was growing up. Her need for care had created an assumption of dependency and deprived her of capacity. The extent of Michael's incapacity was also subject to being increased or diminished by environmental factors. Although he could walk, albeit unsteadily, his support worker told me that in the new day centre they put him in a wheelchair at lunchtimes to avoid him bumping into another people and to be sure of a quick exit in an emergency when the dining room was busy. The workers therefore managed deficiencies in the environment by restricting Michael's freedom of movement (F/notes 8/2, p. 2).

It was not only amongst professionals that a need for care could lead to a refusal of capacity. Although Margaret was considered to have profound impairments, those who knew her agreed that she was very alert and aware of what was

happening around her. Margaret's mother said that Margaret was very aware of interactions between people and hated to be ignored (F/notes 2/1, pp. 3-4). Her key worker spoke of how Margaret liked to be around people and looked at everyone at lunchtime, neglecting her food if there was someone there that she had not seen for a while (F/notes 2/3, p. 2). Within the day service, the idea of seeing how she would benefit from education was being explored. Her keyworker explained that there were plans to see if she could go to college the following year with one-to-one support and the lecturer was in the process of trying to set something up: 'She will be the first one with her level of need to try - because she is so aware' (F/notes 2/3, p. 2). However her mother was dismissive of what she saw as unrealistic expectations. She saw 'no point' in the technical equipment being tried to assist Margaret with her communication or in the college placement. 'I don't think there is potential in Margaret', she told me (F/notes 2/1, p. 2). Families therefore could also consider that dependency on care negated other possibilities for the person.

Thus the need of people with profound and multiple impairments was largely met through day services and was construed as a need for care and for respite for families. Complexity of need was responded to by a limited number of models of care, principally attendance at a unit and a higher staff ratio, rather than for example, developing a wider skill base amongst staff. Although health needs were a very important aspects of people's needs viewed holistically, these were not seen as unambiguously the responsibility of day services, resulting in a reversion to parental care when the person's needs became incompatible with the congregate setting, whilst a lack of expertise also resulted in some care practices not being put in place. When care was construed as dependency, needs to develop capacity could be neglected.

3.2. Safety

Requirements for support in the form of supervision to ensure safety could result from a number of different situations including the needs of someone

experiencing severe and enduring mental health problems, perceived vulnerability or the risk of self-harm or harm to others. I will consider a number of these situations in this section and ask whether these experiences indicate that some claims for support were given priority over others.

Tracey and Anne received additional support at their respective day centres because of behaviours related to their mental health problems and their perceived vulnerability. Tracey had received a diagnosis of severe and enduring mental illness and was receiving regular medication. Support was eventually found for her at a specialist centre where a case review described her as a vulnerable young woman who would be at risk of exploitation if she went to community facilities unaccompanied (O.T. assessment in F/notes 7/12, p. 5). Her mother also described Tracey as 'very, very vulnerable' and said that if she went to buy something from a van she would not know whether she had the right change or not (F/notes 7/4, p. 8). Her support worker at the centre told me that Tracey had approached a man she did not know and asked if she could go home with him. She felt it would be years before Tracey (then in her early 20s) would be able to travel independently. Diagnosis of her mental health problems, followed by recognition of her vulnerability, constituted the case for why she was being offered additional support.

Anne's behaviour caused her parents and sibling a great deal of concern and they felt that 'she needs supervision at all times' (F/notes 3/3, p. 3). Professional assessments did not necessarily concur. Anne's mother recounted how a period of extensive assessment of Anne by 'lots of experts' had resulted in judgements about Anne's capacities that made her feel a failure as a parent.

And when they said Anne should be doing other things she had felt that she wasn't being a very good mother. She'd felt inadequate because of the things that they were saying, that she should have been able to get her daughter to do more when she knew she couldn't (F/notes 3/3, p. 3).

At the time of the research Anne's parents were seeking a new assessment of Anne's mental health as they felt that her behaviour was deteriorating. I did not see Anne's assessment and it is possible that others felt that Anne should be

allowed more opportunities to develop her skills and independence. However Anne's behaviour was also considered the family's problem, even though she was a woman in her thirties. A weekly diary kept for the research showed that when she allegedly hit another person who used the day centre, her father was telephoned to collect her and take her home for the rest of the day (F/notes 3/6, p. 3). There were limits to behaviours that could be managed in the day service setting.

Marilyn did not receive one-to-one support at the day centre, but did at home, in her supported living project and she had two-to-one support when going out because of her changeable moods and self-harming behaviour. The level of support she received from her support package contrasted with what had been available to Anne or Tracey. Marilyn had profound impairment, probably related to Rett syndrome. Having got a service package, additional support was made available to provide her with the level of supervision that enabled her to go out into the community. Marilyn felt more secure walking between two people and it was felt that if she got very distressed two people were needed to get her up from the ground and out of the situation (F/notes 4/3, p. 2). Over time the hope was that this need for intensive support would reduce. Marilyn's behaviours, at least in her present care setting, attracted support rather than negative reactions. The level of support made available to her to enable her to go out, evenings included, contrasted with that available, for example to Anne, who attended the same day service.

Rob's situation was very different because he was considered to pose a public risk. He was subject to very close supervision in the community because of concern that he might reoffend. His support workers saw their role as to prevent him getting into more trouble with the police, and to manage his challenging behaviour and violence: 'But when they go out and about one of the issues is to make sure that he doesn't touch women improperly' (F/notes 6/1, p. 4).

They saw the supervision they provided as the last line of protection against an admission to a secure hospital.

So basically they are, if you like, “soft policing” him in the community to prevent an incident that would mean that he couldn’t still live in the community. Otherwise the bottom line is, as I said, if he is up before the Procurator Fiscal again he will go to Carstairs (Transcript 6/1, p. 5).

Similar levels of support had yet to be found for Stuart, Phil, Sheila and Ailsa who were living in secure environments because an appropriate way of managing their behaviour or keeping them safe in the community had yet to be found. The nurse on the long-stay ward where Sheila was living had known her for over 30 years because her own aunt had been a regular visitor to the hospital with Sheila’s mother. She said that Sheila’s many previous placements had broken down because of her behaviour when she did not have enough support around her.

She said that the reason that the placements had broken down is her behaviour, that she can’t cope when she’s on her own, that she screams, she’s violent, assaults people and the police have been in and she kind of thrashes around on the floor (F/notes 12/1, p. 15).

Sheila’s readmission to hospital therefore was related to the lack of appropriate community support or a model of service that could keep her safe and secure.

Behaviours that were related to underlying mental health problems could be interpreted as reasons for exclusion, rather than treatment. For example, Tracey had been excluded from her previous day centre for stealing. Tracey’s mother and her community care manager were in agreement that her exclusion from day services had been unfair and represented a failure to acknowledge her mental health needs.

I asked what was wrong with it (a previous day centre), she said that it was their attitude, they ended up suspending her “kicking her out” and she obviously went to meetings there where they had notes in front of them and this is quote from her, quoting what they said to her “she did this, she did that, she laughs, she knows exactly what she is doing”. Her mother thinks that they should have got to the bottom of the problem instead of punishing her (F/note 7/4, p. 5).

The result of Tracey’s exclusion had been to put her at risk and thus to increase her vulnerability. Tracey’s care manager confirmed that day services had, in her view, stacked the odds against Tracey and set her up to fail. When Tracey’s behaviour had been viewed as disruptive, the service response had been to exclude her.

Even for Rob, risk was malleable, not only according to setting, but also according to the expertise of the person(s) providing support. This expertise could consist in training and knowledge, for example in managing behaviour that challenged, but also familiarity with the person and a good relationship or match between the supporter and the individual. Rob's workers, one in particular, seemed to find danger wherever he took Rob in the community (F/notes 6/2, p. 5). So great was his concern to prevent Rob touching a woman or otherwise behaving inappropriately that going out and about was very restricting. Women in shops wore name badges on their breast that could be grabbed (F/notes 6/1, p. 4), shopping centres had women and children in them (F/notes 6/2, p. 3), pubs had couples present later in the evening. Another of his workers was more relaxed and seemed to find it possible to have a day out with him, for example buying things for Rob's flat (F/notes 6/3, p. 3).

Stuart's discharge from hospital was being delayed because it was proving hard to find the resources to provide adequately qualified (nursing) staff to supervise him in the community. His requirement for supervision was mandatory as it was a condition of his detention. It was considered essential for Stuart's mental wellbeing that he could continue in the community with the art work he did on a daily basis in hospital and for this, he would need an escort to a suitable art project. I recorded an account of how the nurse in charge of his ward described his situation:

Five days a week this job he has in the therapy unit is actually art work. He should have already gone to [name of project] but the psychiatrist is worried he won't be able to access the services that he needs. Basically, with the level of supervision he's obliged to have because of the Section, it's not clear that they could guarantee to get him an art facility like he currently accesses in the hospital and in his own words "if he can't do that, then he's bad". So these are what she described as "quality issues", that he'll get an en-suite bedroom there but it doesn't mean he would get access to all the things that he needs. And there's a certain level of training of a person, first level nursing person, who has to supervise him when he goes out and she says they don't have that level of staff (F/notes 13/1, p. 29).

So because Stuart could not access the therapeutic occupation considered essential for his safe management and wellbeing, he remained in hospital.

There seemed less certainty both about the justification for support and the appropriate model of care for needs related to mental health problems compared to needs related to physical dependency, and there was a different response to someone who might pose a public risk to people who were vulnerable. The two individuals living with families seemed to find it harder to access intensive support than Marilyn, who lived in supported accommodation. Perhaps this was because she had been in a decommissioned hostel provision and the funding was therefore available, or because she had been a state responsibility since childhood. There seemed no limitations on the support hours available to Rob who was considered a risk to others and to women and children in particular. Again this contrasted with the view about Anne, whose behaviour mostly affected her parents, although it also limited her own inclusion. Tracey was highly vulnerable and yet was actually excluded from services, exposing her to further risk until external funding could be accessed. Public risk therefore seemed to provide a much stronger claim to intensive support than burden on the family through profound impairment or mental health needs. Four people were not yet discharged into the community because of the problem of organising appropriate support. The case for supervision, whether to prevent harm, manage behaviours or enable independence, seemed more open to dispute than the case for care. This may have reflected boundary issues between health, criminal justice and social care with both the need for and the response of supervision being more readily accepted by the first two. When the support provided was to supervise behaviours it could vary from very protective (Anne's family or Rob's support) to enabling (Marilyn); it could restrict freedom or enable it as much as possible, even for someone who was deemed at risk.

3.3. Independence and inclusion

One-to-one support could be in place to promote inclusion where the individual had challenges that made this more difficult. For example, a befriender had recently been found for Ruth as a way of extending her opportunities and overcoming some of the challenges related to her sensory impairment and mental health needs. A placement one day a week in a specialist centre for her

sight impairment was having a positive impact on her quality of life. She was being taught to use a roller ball cane and could walk down the middle of the corridors instead of needing to stay close to the wall. In this smaller centre the environment was better adapted to her, whereas in the other day centre she 'sits with her head in her hands' (F/notes 5/2, p. 4). However the availability of resources limited Ruth's access. Whereas staff in her project would have liked to see her at the specialist centre for two days a week, there was a long waiting list.

In her new day service, where Tracey was seen as 'vulnerable' rather than 'bad', the response offered was training in life skills, rather than exclusion. In her day centre, which specialised in supporting people excluded from other services, Tracey had a clear programme and staff were working with her on issues such as her giggling and laughing in the wrong situations. The assessment recommended two-to-one support initially (F/notes 7/12, p. 4), but also identified constructive approaches including the need for her to be supported to mature in a safe setting, to access new leisure opportunities, form friendships and take on responsibilities (F/notes 7/12, p. 5). Her individual personal plan set goals to develop skills that would increase her independence and help her keep herself safe, including encouraging her to see herself as an adult. Thus it included prompts to support her concentration, such as getting the bus to stop at the right stop, but also appropriate behaviour with strangers (F/notes 7/12, pp. 1-2). Her support plan showed that protection and the development of skills could be combined.

Ailsa was now in a secure setting. She had a long history of having been at risk of harm. Whilst she had had a happy time with foster parents, who had died, she had been exploited in her own and other families. She had had also some bad fits recently and she was being seen by the doctor for a swollen stomach. There were reports of physical and sexual abuse in more than one setting and of having a house before but something horrible having happened to a neighbour which had upset her. Ailsa's first priority was to have a home of her own. In the short time that I knew her she rearranged the furniture in her room to make it more homely. She longed for a home with a front and back door where she

could hang her washing out the back to air, establish her routines and keep her house in order. As she explained, 'When I get my house, I'll put my washing all out' (F/notes, 17/2, p. 20). It would be quiet, unlike the place she was currently living in. She knew that this assessment of where she should live was also the expert view: 'The doctor says I'm better, I'm better having my own house' (F/notes 17/2, p. 15).

Her other wish was to belong to a family. As part of the process of preparing her for community living, she had been staying at weekends with a worker from the provider who would be supporting her, and they had accepted her into their midst; she even wanted to change her name to theirs and felt that they were now her family.

Sally's mum, Sally's mum makes me a lovely tea. She's brilliant, Sally's mum. All her family's brilliant. I love her family. Everyone in the family. I love all in the family. And I love my new mum. I've no got a dad but I love my new mum and I love all my new brothers and my new sister-in-law and all my wee, my wee new nephews and my wee niece and Sally's two, my two brothers (Transcript 17/3, p. 6).

Ironically at the time I met Ailsa, the exploitation she had experienced was being responded to by placing her in a secure environment. She was paying the cost of the harm that others had inflicted by having her liberty restricted. However her wish for a home and family represented an aspiration of how she could be supported to overcome past hurts and have a better future life. It can stand as an illustration of the possibility for support that would be emancipatory rather than harmful; her chosen solution would have enabled her to enjoy more reciprocal relationships and exercise her capacity for mutual care.

Whilst inclusion and independent living were goals of care for some people, support to develop communication capacity seemed a lower priority. One young woman I met at a day centre took part in whatever was going on and communicated as best she could without much use of speech, for example hugging me when she heard I was leaving. It emerged in conversation with staff that while she was at school she had had equipment (an alpha talker) to assist her communication but that 'education won't release it' for use in the day centre and in any case day centre staff were not trained in its use (F/notes 1/1,

p. 6). Deprivation of speech was therefore not a sufficient priority to overcome barriers to resource sharing within the local authority. Staff shortages were a problem in developing the use of the specialist communication equipment that Jennifer, Margaret and another person had been assessed for. Jennifer's keyworker also raised the issue that the day centre was not within the catchment area of the advocacy project, although they sometimes took people from the day centre there anyway (F/notes 1/1, p. 6).

It is striking that learning disability by itself, whatever the level of the impairment, was not the only or even primary reason given for a high level of support and nor did communication feature as a priority for intervention, even where the development of greater independence was identified as a reason for care. Some people therefore did not have access to the most basic requirement to enable them to exercise autonomy and choice. However there were examples of support being offered to develop skills for more independent living to people in very different circumstances. High levels of care and protection were therefore not necessarily incompatible with more enabling approaches, but these were not always available. In particular there was a neglect of the importance of providing people with communication needs with access to the support they required to indicate their own needs.

3.4. Conclusion on reasons for intensive support

In this section on the reasons for which people received a high level of support I have shown that some needs had a higher claim on intensive support than others. On the whole, care and protection seemed more easily recognised as claims for intensive support than were mental health needs or support for independence. What constituted a 'high support need' was subject to interpretation and was no guarantee of a service; someone who was highly vulnerable, for example, could be excluded from provision. Moreover families were still seen as the default providers of care, suggesting that, even where there was a high level of need, the status of care needs as public responsibility

was not firmly established and applied only in certain circumstances. In a social care context, challenging behaviours, health needs, and in particular fits and repeated infections, were disruptive of the care environment and could literally be exiled from these spaces back to the home, even if this left the person vulnerable. The very needs that constituted the claim for additional support could result in exclusion, reinforcing the norm that they were not part of the core business of social care. The designation of some health needs as 'additional' may symbolise a dispute over a responsibility for funding and care between health and social work services; day care had not assumed responsibility for dealing with health-related needs. When the person did not live with their family there were examples of support put in place in an attempt to meet these needs and there were also examples, from those people still in long-stay and secure settings, of an absence of alternative models that could adequately meet such needs. Fairness was not the outcome of differential responses to needs claims.

The three rationales for providing additional support identified from the data (physical care, supervision and inclusion) could be seen as different discourses about care: care as dependency, as discipline and as emancipation (Hughes et al., 2005). Construed as a response to dependency or as discipline, care could be characterised as much by the needs it failed to meet as by the support that was provided; Ailsa's hopes showed that an alternative vision was possible in which the provision of a safe rather than a restrictive, environment might make mutual relationships possible.

4. Struggles over interpretation of needs

This section considers in more detail two situations where there were struggles to establish needs claims. I have highlighted them because they indicate some of the barriers to accepting certain needs as legitimate cases for the allocation of additional resources. In the case of Michael, the young man with profound and multiple impairments, his requirements appeared to exceed what was

considered reasonable for an adult day service. The second example concerns the struggle to find funding for Tracey, despite her acknowledged vulnerability. Both examples show how making the case for additional support required an attempt to legitimate a needs claim and that the struggle to do this demonstrated the assumptions underlying resource allocation systems and their consequences for disabled young people and their families.

4.1. Excess need

I will first outline the history of the struggle to find ways to provide Michael with support throughout the week and then look at the nature of the disputes and what they may say about the norms for resource distribution in adult services.

Michael had been at a special school for children with complex needs since the age of three and it was when, at the age of 18, he required adult services that arguments about responsibility for meeting his needs began. This was just before the introduction of community care. He was now 26 and the latest episode was just being resolved at the time of the study. I have put together an account of the story of the attempt to secure a sustainable package to meet his needs from his mother, the social worker (in the area team), his current day centre manager and assessments from his file.

This is the history of Michael's care package, a history that spans the development of community care itself. When the day centre manager visited his school, after his initial assessment for a full-time place, she deemed that Michael needed two-to-one support, largely because of his epilepsy, and that this was beyond the capacity of the centre, where the highest staffing ratio was one-to-three. So he was sent to another centre, 25 minutes journey away, but this centre was unable to meet his needs. He was then admitted for assessment to the local centre his parents had wanted in the first place, 'under duress', according to the centre manager. They tried to work with him within their existing staff ratio and found that other people got neglected. So the case had to be made for additional support and when Michael was 20 (1993) a review

ensued resulting in the completion of a community care assessment for 16 hours home support and day care to enable Michael to attend the centre with one-to-one supervision. Michael's mother now had him at home for one day a week and two afternoons and she had lost the volunteer helper who had supported her in the mornings for the time he was in education. It seemed to her that the co-ordinated service Michael had had at school had broken down and she was concerned that the sustainability of the service seemed in doubt.

Some short-term solutions were then found to support Michael at the day centre, such as a trainee social worker, but eventually two home support and day care workers, who combined to make a full-time equivalent post, were allocated. Then one of the home support and day care staff left and a new solution was found which the district council underwrote. The council funded a Community Service Volunteer (CSV) from overseas to assist the home care support worker. The CSV volunteer worked for a small fee plus his accommodation and the total cost of extra staff was less than that for the day centre officer. This was the arrangement in place at the time of the study and Michael and his family were receiving support from the day centre for four days a week and six-weekly respite, while some support at home (provided by the same home care support worker) was funded through the Independent Living Fund.

Throughout the years there was no dispute either about the level of Michael's needs or the responsibility to support Michael's mother. According to his social worker 'the need for support for the user's mother is an identified need and would be seen as a priority' (F/notes 8/7, p. 1). Nonetheless the level of support that the social work department should fund was contested and the struggle was played out in terms of a long-running argument about whether a five-day package was affordable and who should take responsibility for funding the two-to-one support. The area team argued that funding should be provided by the council centrally and the council insisted that the care should be provided by the day centre without additional capacity. The professionals involved with Michael's care expressed frustration at the inflexibility of the resource system to

meet his needs. For example the social work review at the time of his assessment for home support and day care read:

Workers are all agreed that the present haphazard arrangement is not ideal. Michael needs all the stimulation/activity he can get and carers need maximum support if the strain of caring for Michael is not going to necessitate his going into a residential unit at a future date. Carers do wish him to remain at home and are well motivated to provide this care. They will only be able to do so with support from our department (File extract in F/notes 8/6, p. 25).

The home care staff who were brought into the day centre were funded from Michael's local social work area team, but this was considered such an unorthodox arrangement that it had to be kept quiet. The centre manager said, 'But I was told not to tell the district manager ever that we had home support and day care workers in day care units' (Transcript, 8/6, p. 4).

The family's private need for support did not exert a sufficiently strong claim on the system for resources and this devaluing also reflected on the additional workers. The home support and day care worker who had supported Michael for five years commented on how the package had worked because he had never had a day off sick and had continued working when he had a broken ankle because there was 'no Plan B' for Michael. He did not enjoy the terms and conditions of a day centre officer.

Despite the fact that Michael's needs were not disputed and the importance of supporting his family was agreed, there was a titanic struggle over many years to assemble funding. The intensity of support that Michael was deemed to need by the day service apparently broke the rules of what each budget should provide. All sorts of attempts were made to work round the system by providing temporary staff funded from other budgets and the situation was experienced by his family as uncertainty about whether Michael's needs would always be met. Adult services, as an administrative system, were not equipped for Michael's level of need, although the workers eventually assigned to him were able to manage these on a daily basis. However their marginal status reflected the ambivalence about responsibility for meeting Michael's needs. Lack of flexibility, both in terms of budgets and the deployment of staff, limited his

family's choice and the service that could be offered to him. Money and staff were allocated to services, rather than the needs of the person determining the allocation of funding and the organisation of human resources. Although Michael's needs were at a very high level, support was dependent on the outcome of disputes over resources, not as a right.

4.2. Vulnerability

I have already described how Tracey had been excluded from day services but eventually, following diagnosis of a severe and enduring mental health problem, was found a place in a specialist centre with one-to-one support in order to support her to become less vulnerable. Tracey was not unknown to services. Like Michael she had attended a special school. She had strong advocates in her community nurse, her community care manager and the community care senior in the social work area team where she was assessed. However collectively they were unable for some time to make the funding regime work to provide support for Tracey and she was left without a service, during which time she was abused. Services therefore failed to protect her from harm.

Again the level of support which she required was seen as exceeding acceptable limits, as the senior social worker explained:

He has pursued this issue with senior social work commissioners and they say there is no funding for people in that category. He drew up a specification for someone to get two-to-one support, but the council wouldn't allow it (F/notes 7/10, p. 2)

Over a period this social worker explored various ways of supplementing the funding package, including access to Independent Living Fund money. In his analysis, the problem was the funding model within social work which he felt needed to be 'shattered' and accountants brought in to show people how to do things differently.

He says they are still having trouble trying to finance a package for her. Stuck. Ironically "to my shame" the health board is being more flexible than social work that still have problems. Social Work find it difficult to be imaginative and flexible (F/notes 7/2, p. 1).

The risk to Tracey could not be managed within a system where health and social care budgets were separate and there were inflexible limits on what any particular service could provide. The maintenance of spending limits within the resource allocation system was at the expense of preventing an individual crisis and the cost was therefore transferred to the person who became more vulnerable as a result.

In these two examples the individuals and their families were effectively disempowered by a system of allocating resources that was resistant to exceptional needs, while frontline managers acted as advocates to make the case why they should receive two-to-one support. There was a struggle between families, health professionals and a local social work team on one side, and the council's central resource allocation panel on the other. Pressure to allocate funding because of needs being experienced at the frontline was being resisted centrally and in the struggle, new needs were being brought to attention, exposing the inflexibility of the existing system of matching resources to needs.

Fraser (1989:171-3) describes three kinds of discourses that occur when there is a political struggle to establish a new need: 'oppositional talk' that politicises a need from below, 'reprivatisation talk' that articulates previously taken-for-granted entrenched resistance and 'expert' talk which begins to translate the politicising movement into reasons for state intervention. In the course of this study the third stage of the struggle, as set out by Fraser, began to emerge in the form of the development of self-directed support which emerged as a response to systems of social care that treated the allocation of social care resources as a gift rather than a right (Duffy, 2006). I visited a council that had started to pilot ways for individuals with high support needs, albeit if necessary with their families or another person who knew them well 'interpreting for them', being enabled to take more control over commissioning the services that the allocated budgets would provide.

So as time has progressed, I suppose [we have developed] the kind of sense that ... we have to not only think about planning as individuals but as the response as an individual and the money around that person as the individual and... not look at service costs but individual costs and so far as providers or our own providers or any providers it's

broken into the support for individual people that makes up an overall budget, rather than an allocation per se (Transcript, DT/1, p.1).

These developments were initiated in order to bring about change in traditional services by altering the power relations and enabling 'service users' to have direct access to control over how resources were used. The examples that I have described illustrate the struggles within social care out of which these developments to change resource allocation systems originated. The process of politicising needs proposed by Fraser illuminates the relationship between 'excess needs', a funding system in crisis and attempts to re-engineer a more just system.

5. Conclusion

In this Chapter I have argued that certain needs were perceived to constitute stronger claims for public resources than others. Complete dependence on others for care or a risk of harm to self or others was seen as a stronger claim for support than mental health problems or challenging behaviour. The priorities were reinforced by inflexible resource allocation systems, traditional service models (including the separation of health and social care) and an implicit hierarchy of impairments. Thus the way that needs were prioritised, the situations in which managers had to struggle for resources to respond to identified need (which I have described, following Fraser, as 'contested needs claims') and the tensions between care and inclusion that frontline staff had to manage resulted in a systematic marginalisation of support for needs related to communication, autonomy and wellbeing. There was an inherited lack of investment in facilities and expertise to safeguard and promote these 'softer' needs. Three results followed:

- despite high cost support packages, people's needs were not met holistically;
- there was a lack of fairness and rationality in resource allocation; and,
- incapacity and lack of autonomy were reinforced.

Normative judgements came into play about who should receive resources in the form of public services. These judgements were not value-free and all claims were subject to interpretation. There were struggles to resource care packages for someone with a very high level of care need and someone with demonstrable vulnerability. The reluctance to accept complete responsibility for these needs seemed to reflect implicit judgements that people with profound impairments were primarily the responsibility of families, with the state offering limited 'relief' in terms primarily of day support, that mental health issues were also private concerns unless they resulted in behaviours that were a public problem and that the support required exceeded the level of funding that was considered acceptable. Levels of perceived need could vary according to the assessor and the environment that the person was in. A focus on the tensions and contradictions in the category of 'high support needs' has therefore highlighted a number of features of the dominant system of resource allocation, and has relevance to wider debates about the allocation of social care resources.

In this chapter I have discussed some issues in identifying and meeting needs in the light of the debate about recognition and redistribution. The distribution of resources did not follow equitably upon the demonstration of need, rather a claim had to be staked for some needs to achieve legitimacy. 'High support needs' were actually claims on behalf of people whose status as recipients of public support was not fully agreed, and for whom the means of meeting needs was primarily limited to the proposal for additional staff. Therefore it would require their rights to equitable treatment and autonomy to be accepted, before their case for support would be likely to be successful. Without recognition of the legitimacy of claims to support autonomy and wellbeing, the 'fair' allocation of resources will result in the continued and systematic marginalisation of people who challenge services, even if they are assessed as needing a high care package. Fraser's emphasis on the question of how needs enter the public arena as claims to entitlements, provides a link between the social care discourse of needs and issues of justice and citizenship. The implication of my argument is that unless the human rights to fairness, respect, equality, dignity and autonomy are recognised as claims for social support, people with learning disabilities who have profound impairments, mental health problems, and communication difficulties, cannot access the means to citizenship, and will continue to be seen

as marginal claimants in the struggle for resources, a marginalisation which will be reinforced by social care resource allocation systems which adopt a primarily dependency-based model.

CHAPTER SIX Being and Belonging at Home and in the Community: The meaning of social inclusion

1. Introduction

This chapter considers the places, relationships and routines that constituted people's everyday lives and examines how far these enabled the person to be and become themselves, to form and sustain relationships and to be valued by others. I use the term 'social inclusion' to denote the aspiration that people with learning disabilities should be not merely live outside institutions, but should be enabled to take part in a wide range of opportunities within society as envisaged by 'The same as you?', including the experience of home life, meaningful activity, and a social life, as well as friendships and leisure.

In Chapter One I noted how 'ordinary life' principles, developed in the 1980s, had shaped understanding of how best to achieve an improved quality of life for people with learning disabilities (King Edward's Hospital Fund for London and King's Fund Centre for Health Services Development, 1980 reprinted 1982). John O'Brien's Framework of Service Accomplishments (O'Brien and Lyle, 1987, 1989) was influential in identifying principles that service providers should adopt (community participation, promoting choice, supporting contribution, encouraging valued social roles and community presence) in order to enable people with learning disabilities, their friends, families and community members to create more valued experiences for themselves. He identified 'valued experiences' as: growing in relationships, making choices, contributing, having the dignity of valued roles and sharing ordinary places (1989:23). More recent strategies have put less stress on normative understandings of the good life, and a stronger emphasis on reducing inequalities and on the human rights principles of fairness, equality, respect and dignity as the means to improve the life chances of people with learning disabilities (Department of Health, 2007b, Joint Committee on Human Rights, 2008). As I have already suggested (Chapter One), 'The same as you?' referenced both 'ordinary life' and human rights principles

and was also positioned as part of the Labour Government's policies of equalising access to opportunities, therefore reflecting a particular approach to achieving social justice (Lund, 1999).

This chapter examines the daily experiences of the participants in this study in order to understand what social inclusion might mean for them. The Topic Guides for the research sessions and interviews can be found in Appendices 11 and 12. In the interviews and fieldwork I set out to explore three dimensions of the participants' lives and social worlds. The first dimension was their experience of home. My purpose was to identify what 'home' might mean to them, as well as how where they lived promoted or obstructed their inclusion. Second, by a mixture of interviews, diaries and observations, I looked at how people spent their time on a daily and weekly basis. Third, I spent time with the study participants in a place that was important to them and explored their feelings about their community, however they might define it. Shared spaces are an important tenet of 'ordinary life' principles and I wanted to know both where participants spent most of their time and with whom, and also where they felt a sense of belonging. A cross-cutting theme across all three dimensions was relationships. In my interviews with carers I asked about significant relationships and I tried also to find out from the person themselves and through observation, who mattered to them in their lives and what they gained from and gave to these relationships. By considering these four dimensions I hoped to gain some understanding of the features of the participants' daily lives that promoted their inclusion, as well as those that might limit it.

I begin in Section 2 of this chapter by considering 'the meaning of home' for the people in this study. 'The same as you' affirmed the policy that no one should have a hospital as their home and a 'home of one's own' has been identified by people with learning disabilities themselves as a priority for realising security and independence (Curtice, 2006). O'Brien posited three essential dimensions of a home of one's own: a sense of place; control over the home and the necessary supports for living there; and, security of place through tenure or ownership (O'Brien, 1994). Annison (2000) argues that 'home' has often been misapplied in services for people with learning disabilities to settings that were

anything other than homelike, and that the desirable characteristics of a home have tended to be defined primarily by the wish to avoid recreating institutional features, such as large numbers of residents and lack of personal choice. He points out that there are few accounts of how people with learning disabilities themselves conceptualise home and its meaning or usefulness to them. I will examine the extent to which the individuals in this study recognised these qualities as important aspects of 'home', and whether the places in which they lived provided positive experiences that might enable their inclusion.

Section 3 of this chapter, 'an ordinary day?' considers how people spent their day and leisure time and how meaningful these experiences seemed to them. Having something meaningful to do during the day, such as paid employment or fulfilling activity in some form, has also been identified in government policy as desirable for people's dignity and an important aspect of having access to the same opportunities as others (Scottish Executive, 2006). Access to opportunities for learning and leisure are ways not only to have a varied and enjoyable life, but also to extend experiences, develop new skills, meet new people and develop relationships. These opportunities may be particularly significant for adults who have a history of restricted opportunities as they were growing up, and especially so for adults with learning disabilities who may need longer to learn new skills and form new relationships.

Section 4 is about where participants seemed to belong, their experiences in public spaces and strategies that were being used to enable them to become part of their community. Belonging is a goal of being part of 'an ordinary community life' (King Edward's Hospital Fund for London and King's Fund Centre for Health Services Development, 1988). Ward (1990) identified three strategies for making this happen - a companion, a role such as paid employment or volunteering and the opportunity for reciprocity. She commented that it was perhaps just as well that services had not tried to prescribe how people should attain membership of a local community, but that there had also been a slowness in recognising that people needed support to build relationships. 'The same as you?' policy introduced local area co-ordinators into Scotland for this purpose, to build social capital in communities and to link individual people with

learning disabilities into local activities and make connections with people with shared interests (Stalker et al., 2008). More recently, access to mainstream services, such as the local library or leisure centre, has been campaigned for as an expression of disability equality, and an emphasis put on the need to adapt services so that they are accessible to the whole community (Disability Rights Commission, 2006a). An example is the 'Changing Places' campaign for fully accessible toilets to enable those who need adult changing facilities to be in public places with dignity (Changing Places Consortium).

The narrative of mainstream settings in the community as a locus for inclusion has been problematised. Milner and Kelly (2009) worked with 17 men and 11 women with learning disabilities in New Zealand to develop their accounts of community participation. They found that people often experienced community settings as 'strangers', whereas their experiences of intimacy and belonging were associated with settings such as their vocational centre, although these were also the settings in which they had least autonomy. Hall (2004) investigated the 'everyday geographies' of people with learning disabilities and worked with three groups of people in Scotland to enable them to build up their own narratives. People related how experiences of harassment, for example, in public spaces, such as on public transport, led them to keep to specific sites that they knew to be safe and Hall comments that this represented a limitation of their social worlds (Hall, 2004:302). At the same time the places in which people took 'refuge' and felt valued, such as a disability club, were marginalised in the wider society. I will examine where people felt that they belonged and I will argue that relationship was more significant than location in enabling inclusion.

I conclude (Section 5) by reviewing the implications of the experiences of study participants for strategies to promote belonging and inclusion.

2. The meaning of home

This section starts with an exploration of the meaning of home to the study participants, insofar as I could determine this, and then considers what helped to create, or disrupt, a home environment. In conclusion I relate these experiences to the pattern of investment in services for people with learning disabilities.

Six of the study participants lived in the family home (Jennifer, Margaret, Anne, Michael, Mairi and Tracey), four in some form of supported accommodation (Marilyn, Ruth, Rob and Colin) and four in a long-stay hospital or NHS continuing care facility (Sheila, Stuart, Phil and Ailsa). In both family and residential settings, home could be a place of self-expression and where someone was accepted and secure. Personalising physical space could help to recognise someone's identity and promote their choice. Jennifer and Margaret, the two young women with profound and multiple impairments, and Tracey, the young woman considered to be vulnerable, all had bedrooms that reflected their personalities and choices. This was where they kept valued possessions (F/notes 1/3, p. 1; 7/5, p. 6). The first thing that Tracey did, on arriving home, was to check that her teddy bear was still in place on the bed.

Jill explained that Tracey really liked her mum to answer the door and if she didn't, she wanted to know why. She expected her mum to be there when she got back, and the first thing that Tracey would do when she got home would be to dash up to her room and make sure that everything was the way she had left it, and that she had a teddy on the bed (F/notes 7/5, p. 1).

For Tracey, home was where the people and possessions she cared about could be safely relied upon. For Marilyn, a young woman with profound disability who now lived in a residential project, but had previously shared a room in a 30 bedded hostel, her room was a place where she could be private and in control. It had recently been refurbished with pine furniture and had a Java lamp and lights and mobiles that made a noise. Her carer said that Marilyn liked to relax with the curtains drawn and the lights on (F/notes 4/1, pp. 2-3). Marilyn was now allowed to be alone in her room for periods, whereas in the hostel she had been monitored by an alarm because of the risk that she would self-harm. One

way in which she could now demonstrate control was to withdraw to her own room when she wished.

She [support worker] said that at home Marilyn likes her own space, it's her choice when she comes into the living room or not. But she quite likes to be at home, like all of us. And that's how the worker expressed it, like the rest of us, that was her private space, that was her "safe" space (F/notes 4/2, p. 5).

For Michael also, home was a place of refuge and security. There he could move around without fear of bumping into others, whereas in the day centre his irregular gait and tendency to lie down and sleep suddenly could be seen to cause safety issues (F/notes 8/2, pp. 2,4,9; F/notes 8/8, p. 14). Ruth's sight loss did not prevent her from finding her way around the residential project; she made her way back to her own room with ease.

Ruth sat me down beside her on the sofa. We spent all the time there [the front room] except when she took me along to her room to get her money which she subsequently held and fingered throughout the session. It was interesting to see that once guided through the door, she could easily get to her room and find what she wanted out of it (F/notes 5/2, p. 2).

This was in contrast to the discomfort she exhibited at her day centre where the manager of the project reported that she would stand in the corridor with her hands over her face. Home was a place of routines which provided the comfort of knowing what to expect. Love and care contributed to these routines.

A powerful meaning of home was being close to the people who cared for you and whom you cared about. Jennifer, Margaret and Michael all seemed to experience 'home' through the strength of family relationships there. For Jennifer and Michael this closeness was expressed through family routines which, it was hoped, also had meaning for the young person. In the evening Jennifer liked to watch 'Countdown' and her mother said that then Jennifer knew that it was nearly tea time, she would start to make clicking sounds with her mouth and looked out for her father about to go on nightshift (F/notes 1/3, p. 1). For Michael there was a daily routine that enabled him to spend some relaxed time with his father (F/notes 8/8, p. 14). Home for Margaret seemed to be about being close to family members and may also have been the site of shared memories. Margaret's mother spoke of her daughter's closeness to her father during his final illness (F/notes 2/1, p. 3). Love and pride created an atmosphere

of acceptance and family photographs displayed in Margaret and Michael's homes conveyed how this led to inclusion in significant family events such as weddings (F/notes 2/1, p. 9; F/notes 8/8, p. 15). The quality of relationships was paramount in creating the home as a place where the person could be themselves, feel loved and experience freedoms.

For Phil, home was family and friends and by extension, his community was people who communicated in the way he did (by sign). By writing the name of his birthplace, he indicated that he regarded that as his home, and not the locked ward where he presently lived.

So then Phil really got into it and he started to write down the names of people he knew and he wrote "Fred and Jack and Rick and Alistair", and Pete said that Rick was a former support worker, the others were support workers who signed. And Pete said then that he was going to ask a very direct question and he said "right" and he went through the list "Greg, do you like Greg?" and Phil signed and nodded "yes". "Pete, do you like Pete?", "yes". ... And then he wrote down something, and I looked at it and I said, "oh Graham Stone" and then we all laughed, because of course he had written "Grahamston" and Pete looked very surprised and he said "that's where you lived before isn't it?" and Grahamston is clearly his family home. Then he wrote down "Sarah" and "mummy" and then, when prompted by Pete, he also wrote "daddy" and Pete asked him to tell me who these people were, who Sarah was, and Sarah was his sister. So this was his home, Grahamston. And he wrote "F" and "L" and "Len" and this was Falkirk, where he went to school and Len, his friend at school. And then he wrote down "Bill White" and "centre" and Pete said that Bill White was the one member of the 14 staff at the Meadow Day Centre, where he used to go, who signed and that he'd been there six or seven years ago. I then asked if it was possible to ask whether he thought of the hospital as home and Pete asked him something like, "this hospital, this is your home now isn't it, is this your home?" and Phil said "I like my own home, I like my own home", or rather, he signed that, and Pete again was slightly taken aback, and said "well of course he'll never go there again" (F/notes 15/1, pp. 2-3).

Phil therefore was making a clear distinction between somewhere where he had a history and with people he felt an emotional connection to, and the place he lived in and he was able to resist the suggestion that the hospital was now his home.

Personal space, safety, closeness to significant people, and the experience of being accepted and loved, were therefore aspects of the meaning of 'home' to

participants in the study. Home was a space to feel safe and be wanted in. Absence of one of these characteristics could also help to demonstrate that the person was not living in a 'home'. For example, whilst relationships were at the heart of the home, a shared social space could be problematic when the person did not get on with all their fellow residents and people could be vulnerable as well as safe in the place where they lived. Marilyn had derived considerable personal benefits from being supported in her current placement, but she had never been fully accepted by the other female resident who had lived there before her. She was frightened of one of the other two male residents who attended her day centre (F/notes 4/1, p. 1; Transcript 4/3, p. 10-11). Stuart, detained long-term, was facing court for a further accusation relating to his time on the locked ward (Transcript 13/1, p. 1). Colin wore headphones at night to keep out the noise of another resident (F/notes 16/1, p. 11) and noise was one of the reasons that Stuart had asked the doctor to transfer him from his previous ward. His mental health had deteriorated after the death of his sister and on top of the restrictions to which he was subject, the ward environment made him feel worse.

They put a, what you call it, [restraining order?] to sustain me to stay in the one place all the time. And I had to go about with them all the time. Couldn't get peace, couldn't get peace to be on my own. And we can't hear properly and with them banging ... about and everything and television on full blast (Transcript 13/1, p. 3).

Some of the social meaning of home could be lost when relationships were not continued. Marilyn's situation illustrates some of the complexities of relationships between significant others and home. She had spent her childhood in children's homes, but her support staff sought to maintain links with a relative through photographs in her bedroom. One of two workers who had known her best, having supported her in the large hostel where she had lived before, was now working in her day centre but was no longer her key worker there and had no link with the provider who supported her at home. She reported on the disruption that Marilyn had experienced when she moved into her new home and both support project and day centre staff spoke separately of the lack of shared knowledge between them. One of the day centre workers had taken Margaret on holiday in the past and another had had her to her home. Rather poignantly they quizzed me on what her bedroom was like now: 'Is it

lemon? It was lemon the last time I saw it, the room was lemon, I'm sure it was' (Transcript 4/5, p. 21). Marilyn had therefore lost some of the security of being known in her own home.

There could also be limitations to the home and family environment for the person's self expression and self development. Continuing to live in the family home may make it hard to become an adult when the person still depends on their family to meet all their needs. Margaret's mother was sceptical of the day centre's wish to get her a college place and she felt strongly that her fiercely loved daughter had 'no potential' (for further intellectual development) (F/notes 2/1, p. 3). Anne was strongly included in the family but, like the younger Tracey, was running out of things to do there. Anne's mother and father were finding her behaviour increasingly demanding and difficult to manage in the home and on social outings, and it kept them on edge. Her mother was torn between a medical explanation - Anne's medication needed adjusting - and a social one, as the thought had struck her that Anne, (who was in her early thirties), might be wanting to 'kick the traces' and move out of the family home: 'She's ready to leave home and although they had been aware that this was something they would have to plan for, they hadn't thought about it yet' (F/notes 3/7, p. 2). Indeed Anne's security at home seemed contingent, and by the end of the study she had been moved to a health facility for assessment (F/notes 3/8, p. 1).

Homes were not necessarily open to the wider community. Jennifer's family were fairly isolated in their suburban street and depended for support with caring on their family visiting from some distance; a neighbour who had been involved in the past had now moved away (F/notes 1/3, p. 2). However, this family did have networks amongst other families with disabled members. The project that Marilyn lived in was on good terms with neighbours, but had only occasional contact with them. 'It's really just Christmas cards and 'hi' over the fence', the Team Leader explained (Transcript 4/3, p. 5). A neighbour who was singled out as sympathetic had a son with disability. The next door neighbours to the four person project where Colin was supported were selling their house to get away from the noise of residents (F/notes 16/2, p. 12). Thus, experiences of neighbours was variable, in keeping with other studies (Alphen van et al., 2009).

The value of home, therefore, could be diminished through negative relationships, the loss of significant social connections and the lack of opportunity to move on to greater independence. Opportunities for inclusion in the local neighbourhood could be limited. However there were also ways in which the home could be a bridge into wider social networks. Though centred on the home, the family network could be a way of keeping connections, extending horizons and becoming included locally. Anne was able to keep in touch with a friend from school who had moved far away because her family facilitated the link. Some homes were also bridges into the local area. Margaret went to the local church, a deliberate choice of her mother who had preferred this over a specialist service for people with learning disabilities which she described as 'all candles and a special atmosphere' (F/notes 2/1, p. 2). She had actively managed Margaret's relationships with the local community, doing all she could to have her seen out and about and accepted from the time she was a baby (F/notes 2/1, pp. 8-9). In a residential setting, staff, like family members, could also bring their social resources to enrich the life of the person. Marilyn's new support worker planned to include Marilyn in her life and interests, such as horse riding (F/notes 4/2, p. 5). Her team leader explained how they would work in stages to build up such participation, first getting her used to the horses and the riding centre, then trying to get her to accept wearing a hard hat, 'But that is an example, totally, of where staff bring their own 'community bit' in. And hopefully we'll get going with that' (Transcript 4/3, p. 14).

In conclusion, the study participants did recognise the difference between a home and somewhere you lived. Whilst personal space, a place for precious or familiar possessions and a place to feel safe mattered, home was an affective space, where you could be yourself, surrounded by the presence or memories of those you loved and who loved you. Individual priorities for the home varied: privacy was important to Marilyn, company to Margaret, underlining the importance which O'Brien gave to choice in defining a home of one's own (1994). However the primacy accorded to continuity of relationships in these data suggest that security, which O'Brien considered to be best achieved through ownership, was equally important.

The characteristics of home identified by Annison (2000), the home as physical space, social space and site for personal development proved useful in considering the different dimensions of experiences of home and, as he suggests, where one dimension is lacking, the home may not be meeting all of a person's needs. Incompatibilities between residents could make the social space feel unsafe and a lack of options to move on from the family home could restrict someone's development. Homes could be bridges to the local community, but they could also be islands.

The meaning which the participants accorded to 'home' has implications for services and for how they can promote inclusion. In residential and supported living services, a concern to create an ordinary setting and to provide person-centred support may not be sufficient, unless it includes attention to maintaining relationships that are important to that person. Home also needs to be thought of from a life course perspective. The assumption that with willing family carers, a person has all they need in the family home until that caring arrangement breaks down, overlooks the need of everyone for new relationships and new experiences. Longstanding work has shown that it is feasible for people with profound and multiple impairment to live in supported living (Fitton et al., 1995), but this is not a cheap option and seemed not to be on anyone's agenda for the families who were caring for a person with profound and multiple disability in their own home. This weakened the possibility of the home being a place in which the person could grow new relationships and achieve self realisation as an adult.

3. An ordinary day?

In my research I wanted to explore whether there were features of people's daily and weekly routines that affected their chances of spending their time in activities meaningful to them, and which features of their day affected their

capacity to engage with others. Despite the very different settings in which people lived, and the differences in gender, age and social background of the study participants, there were many similarities in the way that time was spent during the day. An obvious reason for this is that nine of the 14 (all but one of the 10 people who were not living in institutional settings) had day centre programmes for a large part of the week, although the process of diversifying people's time from 5 days a week at a day centre had begun, albeit in a limited way. Moreover, although each day of the week had variety, week on week, the menu was similar. This seems to have been typical at the time, rather than a function of recruitment to the study being partly through day centres. In 2003, the closest year to the study for which figures are available, 85 per cent of adults with learning disabilities known to local authority services in Scotland attended a day centre full or part time (Scottish Executive, 2004). The national statistics do not distinguish levels of impairment and it is probable that the proportion is higher for people with complex needs.

Stuart, in the long-stay hospital, had the most well developed source of daily meaningful activity. He was an artist and his access to art work was part of his therapeutic programme and therefore prioritised. Ironically, the problem of arranging supervision for him to attend an art resource in the community when he could no longer access it on site, was delaying his discharge. Stuart's art gave him the means of making gifts to others and he recounted with pride the pleasure he had given a community worker to whom he had made such a gift. When I visited him some time later in his community home, a piece of his art work prominently decorated the entrance. A gardener, he was also able to rescue other people's failing house plants. Thus there were instances of skills being evident in the private sphere without these necessarily being recognised as of wider public value.

Jennifer and Margaret spent the day from roughly 10am to 4pm based at the special needs unit of a large day centre. Those with profound impairment seemed more likely to spend periods alone rather than in intensive interaction, unless there was some reason that they needed supervision. Jennifer's key worker told me that most activities only lasted between one and one and half

hours because, by implication, staff found it too much to try to occupy someone with profound impairment for longer (F/notes 1/1, p. 6). Intensive interaction is known to be needed to engage with people with profound impairment (for example, Felce, 1998). Many staff did not necessarily have the skills to know how meaningfully to occupy time with someone who required high levels of support. In the unit for people with high support needs, therefore, there was a feeling of time having to be filled, rather than providing an opportunity for interaction.

Margaret seemed to get less one-to-one in the centre, than at home. She spent a lot of time in the other room on the mats, listening to music. I noticed one of the staff go and lie next to her for a bit, once someone moved the chairs. I went and sat with her for a bit (F/notes 1/1, p. 3).

It seemed that it was a challenge for the staff to spend time individually with each person and to deal with the wide range of needs, despite the higher staffing ratio in the special needs unit. In the second day centre Michael's situation was different as he constantly had two-to-one supervision because of his epilepsy. His worker and the volunteer were often able to commandeer a quiet space and the jacuzzi at this centre (which was more newly built) and this enabled them to manage Michael's need for physical relaxation and the fact that he often slept (F/notes 8/5, p. 3). Constant activity was not necessarily what he wanted or needed, but the issue in the day centre environment was how to manage his changing needs for engagement, rest or care within the routines of the centre.

Although Mairi had different needs and was experiencing the newer form of day opportunities that were not based in a centre, filling the time could still be an issue for staff:

I could hear Molly [outreach worker] to Jane on the mobile, basically asking what they should do this afternoon. I mean Molly is a new worker and she was obviously looking for ideas and I heard her say something like "there's a limit ... to how much you can walk round the shops" (F/notes 11/3, p. 2).

Although alternatives to being at the day centre all day were being organised, the routines at the centre resulted in these being telescoped into a very short time frame and this restricted the opportunities either for engagement or

meeting people. An afternoon trip to a park on a bus from the day centre did not provide Jennifer with opportunities to make new relationships. Jennifer's eyes were closed throughout the walk, the visit to the duck pond and the tea at the garden centre. It felt as though the trip was about having a break (one worker said 'we've escaped!') and was more about filling time, than any opportunity to help people build connections in the community. The demands of centre routines cut across any chance I might have of making contact with Jennifer on the trip and illustrated how the tyranny of bus times took precedence over relationships.

It was a rush back to the bus. We left about ten to three. Drove back even more like bats out of hell. Jennifer still asleep. She opened her eyes a bit confused as we got out of the bus. She was taken straight away to be changed and the worker waiting to take her to the bus wheeled her straight off. The unit was closing. No time to say goodbye. I photographed the back of the retreating bus (F/notes 1/2, p. 3).

Michael had a well-developed plan to enable him to take part in activities in community facilities, such as visiting the swimming pool. Even so, his workers had to be highly organised to find the time for this. Between finishing lunch and being ready for the taxi to take him home they had at most two hours in which they had also to find time to get him there and back and change him (Transcript 8/3, p. 7). The irregular impact of Michael's health needs actually required great flexibility and responsiveness.

So as I say it all comes down to Michael. When we go in the morning to collect Michael, we can have a programme set out for Michael but we could, just say we were going swimming, for some reason he's had a bad night or he's not had a great day, we would probably think about it and then maybe not go. It just depends. So we have to be very flexible (Transcript 8/4, p. 4-5).

Day centre staff were paid to work between 9 and 4 pm only and where individuals had evening support, this was often funded through the Independent Living Fund. This same pattern largely persisted in the person centred day service attended by Tracey. She travelled in to the centre and home afterwards, again with her day support worker, arriving at the centre at 10 am and walking to the bus soon after 3pm. The limitations of workers' hours and centre routines particularly restricted the availability of opportunities for people with high support needs who needed longer to do things and often had fewer or

shorter windows of opportunity, because of their own health need, to engage with whatever was on offer. The restricted timescale within which the person's day was conducted limited their possibilities for inclusion.

Weekends and evenings provided opportunities for relaxation in both the family homes and the residential projects. Jennifer listened to music and videos in her room between 7 and 9pm (F/notes 1/3, p. 1). She had satellite television so that she could watch the music channels. It is difficult to make judgements about the quality of how people spend their leisure time or to comment on how 'typical' people's evenings were. However Anne and Marilyn were both young women and Anne's mother and Marilyn's team leader both agreed to keep diaries over the course of one week, which affords some possibilities for comparison (Appendix 4). Though one lived in the family home and another in a residential project, there were similarities in their evening experiences. Both had been at the day centre until 3pm, although Anne regularly went to another family for three hours afterwards. They both had some quiet time and also got involved with activities in the household.

On evenings in, active interaction with others is noted on two evenings for both women. Each had two evenings where they were out of sorts for part of the time. Only Anne had visitors (family) and only Marilyn went out with someone she did not live with (a befriender), although Anne met other people while she was out. Anne went out twice and Marilyn once (but there were other day time trips). Weekends seemed less lively in the residential project. What is perhaps most striking is that each was dependent on their relationships with those they lived with (family or staff) for all their leisure time. Just as staff had often to be both family and friends to Marilyn, Anne's mother had to be both mother and girlfriend.

In all settings the greatest barrier to being able to get out in the evening (other than as a family) was the availability of paid support. The difficulty of accessing this could be a serious restriction on people's chance of having any kind of social life appropriate to their age and gender. Restricted and segregated leisure opportunities directly limited people's opportunity to form relationships.

Jennifer's key worker told me that the other attendees at the club that Jennifer went to one evening a week were all from the day centres and so that afforded her no opportunities to meet new people (F/notes 1/1, p. 6). Tracey's life was severely limited by lack of things to do at the weekend and in the evenings, especially as she was felt to need supervision at all times. She had a befriender who took her out for a couple of hours each week, but her mother was fighting for more weekend opportunities for her. Her mother said that in the evening Tracey was often in her pyjamas by 8 o'clock in the evening (F/notes 7/4, p. 9). Colin was in a setting with support, but spent a lot of time watching television (Transcript 16/1, p. 7). Stuart knew that whether he could go out depended not only on staff availability but also on how rotas were organised for each ward and the arrangements for paying staff double time, 'I used to go out at weekends, Saturday and Sunday. But I cannot go out through the week. But now I'll be going out regular' (Transcript 13/3, p. 5).

Days were far from ordinary in the lives of people with complex health needs. The very individual rhythms of people meant that their opportunities for benefitting from planned programmes were very haphazard. However the routines in a day centres could make it even harder to seize the opportunities when a person was able to engage with activities and with others. Days could involve a great deal of waiting around for opportunities, such as trips, that were then conducted in a frenzied rush. This pattern reduced the likelihood of someone with profound impairment in particular, being able to derive meaningful benefit. Staff in the special needs unit did not seem to be trained in Intensive Interaction (Hewett and Nind, 1998) and therefore found it difficult to occupy someone with complex needs for an extended period. It is often suggested that the day centres should be retained for people with complex needs, since they need a stable base for the delivery of care. This argument seems problematic insofar as in the day centre environment the tasks of care and development seemed hard to reconcile.

An important question was why the day experienced by Mairi, when she was supported by the day outreach project, still retained some of the characteristics of a day in the day centre, in its length and the sense that staff were struggling to fill time. Patterns of staff behaviour may persist beyond the closure of day

centres and these can be reinforced by the feelings of the individuals being supported when they encounter situations of exclusion or boredom. Clement and Bigby (2009) examined what happened over time in a project that was seeking to build community inclusion for people with high supports needs who had been discharged from long-stay hospital. They found that, despite training, support staff did not actively promote inclusion and retained values that were inimical to this objective. They conclude that strong leadership is needed in support organisations to change staff perceptions of their role and of the purpose of support.

Patterns of funding and staff contracts led to real restrictions in the support available in the evenings and at weekends. The concentration of resources in funding daytime support seriously restricted the lives of the younger disabled people and their opportunities for mixing with their peers and growing as adults. The requirement for supervision resulted in a double-bind; someone with a particular need to develop independence and life skills like Tracey, was unlikely to have access to opportunities to go out in the evening because of the cost of funding someone to accompany her. I would argue that support to meet health, personal care, education and leisure needs should not be confused with an imperative to fill the day between 10 am and 3 pm. If there were an expectation that adults with profound impairment should move on from the family home to supported living, part of the pressure to provide an all embracing alternative to school or regular employment might be reduced. In the next section I address the question of whether people in the study were able to belong, and not just be present in community spaces.

4. Belonging and inclusion

In order to find out where people felt that they most belonged, I sought to explore the question 'where is my community?'. Arguably my study methods conflated belonging with place, because I aimed to find out from people themselves what an experience of community meant to them by spending time

in a place that was important to them. 'Community' proved an elusive location to find. The environments I visited with people were pubs (two), cafes, a park and a leisure centre (though for a disability sports session). I also had a long bus ride from town to her home with Tracey and her support worker. The park and sports centre trip were part of day centre programmes and were group trips, even though I was there to engage with one person in particular. The contrasting pub visits were evening social time with Marilyn and Rob, both of whom were accompanied by two support workers. These experiences helped me to decouple the idea of location, from belonging.

I hoped that people might lead me on a tour of their community and, greatly to my surprise, the only person who did so was Sheila, one of the long-stay hospital residents. Sheila did also talk to me about trips to the nearby town, and so it would have been possible to follow those up if my main focus had been on the community as defined by others.

Sheila: I go to (name of town), go to (name of town) and back

Lisa: Do you go to the shopping centre in (name of town)?

Sheila: Aye, see all ma pals

Lisa: Oh yes

Sheila: Get ... my cappuccino and cake and all that (Transcript 12/2, p. 5).

However it was within the hospital that Sheila had carved out a space of her own. She took me on a tour of the places on her circuit, the place she collected her paper, the areas she worked in. These places were all those where we encountered people who mattered to her, from domestic staff to managers. One person in particular, a worker from outside the hospital, was especially important to her. Sheila went quiet in her presence and the worker told me she had a special bond with Sheila. Sheila had her home telephone number and when Sheila lived in the community she would ring her when the stress of being alone in the evening became too much. Sheila had had at least five failed placements out of the hospital in which by all accounts she had become frightened while alone and had ended up being charged with assault. For Sheila, people who knew her were her community. A change of location to a mainstream setting would not lead to her inclusion, although she had many skills to make friends and contribute, unless she could be assured of the security to

maintain links with people she trusted. Only then did she seem likely to realise any benefit from having her own house. This experience seems to reinforce Ward's (1990) view that building genuine community belonging for Sheila after discharge might need to involve a mediator, such as the day services worker that we met, and for Sheila to find some distinct role that would put her in touch with people, preferably one that involved payment, something she greatly appreciated!

Stuart was in a transitional stage, waiting to move to what he described, not inaccurately as 'his new unit' in the community, after a lifetime of being institutionalised. As a member of a collective advocacy group he was in touch with his 'community' of people who had moved out of the hospital and was very aware that leaving the hospital represented a change in status. He reported that he had argued with one of the nursing staff about the language used to talk about people after they had been discharged:

In fact they're not cried [called] residents anymore, they're community people, that is the preferred word...I'm telling you they're community people. And they've a right to be out in the community and a right to live in peace, instead of calling them residents, they're not residents, it's not classified as that. She says, ah but they're on tablets. I said that's got nothing to do with it (Transcript 13/2, p. 17-18).

Contrary to the approach of service managers, which was to disperse people and not acknowledge the social networks that had been built up over many years within the hospital, he wanted to retain his existing connections and concerned himself with how they could all find the means to meet up for social events and to share information:

I think it would be better if there was a big place, big enough for to hold everybody that's in the community, which belongs to the hospital and everywhere else, a hall and you can put in coffee units there and they're still just as good, you can still have your dances and parties in the same place and also have meetings in those places too (Transcript 13/2, p. 21).

Support organisations also formed networks within the community. As far as Marilyn's team leader could see, the residential project itself was the most meaningful community that Marilyn had at present. She explained that they always tried to be alert to opportunities to build community links, but that in

reality, their community was the network of staff in their provider organisation amongst the small number of houses that formed their project:

Sometimes if there aren't enough staff here, then you get staff from the other houses coming in. So that opens the network a bit. And then we have a summer barbecue, Christmas party, things like that, where you meet with everybody in a kind of party atmosphere. So I would say the project is possibly her community. You also have people who work at our office up the road come down, and I would say that's quite a significant network because they all know her name and she gradually gets to be familiar with people anyway. So to us, working in the house, that feels more our community than the actual local area (Transcript 4/3, p. 11).

Through the outreach project, Mairi had clearly been given opportunities to try out new things and to take up new activities, such as keep fit and a role as a volunteer in a local charity shop. By all accounts, including her own, she had grown in confidence and now spoke for herself in a way she had not done in the past. However when it came to her sense of belonging, it was the choir at her old day centre that she emphasised. For example, she talked about what 'we' used to do there (see Chapter Four).

These might be considered problematic accounts of belonging, since they stress social connections that had been made within, rather than beyond, services. My focus on trying to understand what the person themselves may have conceived of as their community may have reinforced what they had already experienced and therefore should not be interpreted as the limit of their desires or possibilities for greater inclusion. However these examples indicate a disjunction between a sense of belonging and some experiences of community living. Hall (2004, 2005) has argued that people create their own social geographies of inclusion, which may not simplistically equate with the geographies that exist in policy aspirations and may provide a refuge from experiences of inclusion in some mainstream settings. Milner and Kelly (2009) suggest that by defining community merely as anywhere outside services, policy makers have promoted a disconnection between the locations in which people with learning disabilities are expected to participate and their experiences of belonging, hence their difficulties in developing lasting relationships in these contexts. In the remainder of this section I will consider some of the barriers that people encountered in engaging with wider social networks and accessing

mainstream settings and the approaches that were helping to build their connections and extend their opportunities.

Jennifer enjoyed being out and about. The barriers that she met included barriers to access in a society that was not adapted to her health needs. She liked to go out to dinner in restaurants, but had to have her food liquidised. Feeding her took a long time, said her key worker. The compromise that staff reached was that she would have her pudding while out and her main meal at home later (F/notes 1/1, p. 4). Day centre staff may not have felt empowered to negotiate adaptations on behalf of the people they supported. For others, risk and therefore the perceived need for supervision, was a barrier to greater independence. Anne only lived down the road from her day centre, but she was taken to and from it by the day centre bus because her parents did not consider it safe for her to travel any other way.

We discussed how she got to the Centre. Although the Centre is just down the road, it's actually the bus that picks her up and takes her to the Centre. This was because once when she was walking there she lost her bag with her keys and money and tablets and everything in it. So they feel that that was distressing for her and that it isn't safe for her to go by herself (F/notes 3/3, p. 3).

She did get out and about, but only when taken by others. Tracey travelled by bus with her support worker but there was concern about her and other service users being exploited on public transport; both their behaviour and the trustworthiness of others were seen as barriers.

'cos it's amazing what the service users will go on the bus and tell, you know, like a complete stranger, like how much they have in their bank book or if they are saving up to get something or where they live or their whole life story, you know, and there are some dodgy characters out there that would just prey on the vulnerability of the clients (Transcript 7/10, p. 11).

Colin lived near a shop, but his support workers thought he would run out into the road if allowed out on his own:

He knows where the supermarket is and that is only round the corner, but he would just dash there and so he needs somebody to look at the traffic. He gets very impatient (F/notes 16/2, p. 9).

On the other hand, the opportunity to learn independent travel skills could be a very important passport to greater independence. Tracey's personal plan

(F/notes 7/12, p. 1) identified her strengths in travelling as being able to present her pass to the driver (most service users at the centre wore their passes round their necks all day). Her identified needs were that she had to be prompted to indicate for the bus, and to know when to get off, and also to refrain from staring at other passengers. Phil was being encouraged to get used to the bus, even though he preferred the car, so that he would be better equipped to live outside the hospital. He was also leaving behind other legacies of the institution that would have got in his way. According to his signer, Phil used to walk about with a big teddy bear under his arm and staff always gave him cuddly toys as birthday presents, 'It's not nice walking though the city centre with a 21 year old with a teddy bear under his arm, especially when you know he has a lot more to offer' (F/notes 15/3, pg. 4). Eventually Phil had put his collection of cuddly toys in a bag and not got them out again. Phil's signer was also taking him to his own home on visits to try and model what life would be like outside the hospital. They would go out and buy food and cook it and watch videos at home.

For those who could not travel independently, adapted vehicles were important for their wider inclusion. Adapted vehicles were needed for Jennifer, Margaret and Michael, not only to accommodate their wheelchairs, but to provide space for someone to be with them in the event of seizures. Adapted cars, taxis and the centre bus were therefore their main means of transport because of the lack of public transport with appropriate adaptation⁴. Marilyn did not require an adapted vehicle, but she preferred to go out in the car because she did not like crossing open spaces.

When we came out [of the pub] she knew which car we were headed for and made her way round to that. Sally said that Marilyn likes to keep close to the wall and it's sometimes a bit of a difficulty if they come to a gap (F/notes 4/2, p. 5).

⁴ When trying myself to arrange a city tourist visit as part of a training course that included people with complex needs I discovered that the adapted tour bus only had space for one wheelchair user and that the space was not wide enough for someone with a chair with special hand control. We had to travel behind the bus in his car, while I endeavoured to fulfil the role of tour guide. Moreover the wheelchair user on the bus was not positioned where he could see all the sights.

The reaction of other people to someone with very severe impairments was an issue for both Margaret and Michael's mothers. Michael's mother was still hurt by other people's reactions:

We were going in the car to my daughter's ... and I think my mum and dad were in the car with us, and Michael was at the side window and I was next to him, and there were some boys playing and of course, as soon as they see Michael you feel as though you're the floor show you know, and it can actually spoil a visit. I should be able to rise above it all and just say, "oh they're only kids", but it's very difficult if you've had a lifetime of that. You should get used to it, but you don't really ... it's almost like a bit of a hurt and then you can get angry too (Transcript 8/8, p. 18).

However someone with less visible impairments could also have the experience of being made to feel unwanted, as I witnessed one afternoon when sitting with Mairi in a local cafe. Mairi had been on her mobile, trying to get people to come to her review meeting. She needed a glass of water in order to take her tablets on time:

So ... instead of waiting for somebody's eye, since it was clear they never glanced our way, she called out to one of the main waitresses "excuse me, can I have a glass of water?" and this woman turned on her really, it's the only word for it, and said "Mairi, I'm very busy just now" and she actually put her hand up like a stop sign "I'm very busy just now, I'll be with you in five minutes", you know like she was a naughty child asking for something, and the support worker gave the waitress a killer look and about 30 seconds later she appeared with this glass of water (F/notes 11/3, pp. 5-6).

Although Mairi was actually paying for herself, this was not evident, as the support worker had charge of the money. Mairi was not accorded respect as a paying customer, but was treated very much as a possible problem who was there on sufferance.

Opportunities for people to get to know others and form new relationships did present themselves, but the individuals had to rely on others to maintain these contacts. Margaret was very sociable and had formed a particular bond with two people whom she regularly encountered. One was the disability sports worker and the other was the driver of the day centre bus. There was clear reciprocity in both these relationships. It was the driver who noticed Margaret's fit on the occasion I was out with her and her day centre group. Her attention to the sports worker was rapt, even though the time she spent with him was very fleeting.

Marilyn was supported by the staff of her project on days she was not at the centre, while she also had a befriender. She was taken out to local pubs, for example, and staff tried to provide for her as ordinary an experience as they could. They might have to leave suddenly if she became distressed, but she enjoyed watching others and listening to the music. On the evening I went with her workers chose a pub frequented by other young people where there was music she would like. They told me they did not feel the need to check it out in advance. Once there they asked for a non-alcoholic drink for Marilyn and the bar staff put it in a glass like a cocktail with all the trimmings. The presence of her support worker, who could identify when Marilyn's tolerance had run its course, was essential for giving her the half an hour of enjoying being with other people:

Marilyn stood in the corner for a bit then sat down at another table, really making overtures to other people. She went up to the table with the two people talking, went up to the bar staff who were all very nice. Of the women at the table, one looked a bit unsure, but the other one beamed a smile and said "hello". But it was towards the end of that [time] that the support worker said she was getting the vibes that it was time to go (F/notes 4/2, p. 3).

In order to promote inclusion, it is not sufficient to extend the time spent in mainstream environments or places outside the day centre. By paying attention to people's own experiences it may be possible to get a better idea of what it means to them to belong, whether that is being with people they know, being in certain types of places or doing particular things. This might lead to a more person-centred approach to using mainstream settings and one that might be more likely to lead to presence becoming participation.

This study supports the findings of other work for example, Abbott and Mcconkey (2006), Redley (2009) that the desire to promote inclusion through 'ordinary life' approaches has taken insufficient account of people's actual experiences of exclusion, both spatial and temporal. Understanding these exclusions requires an analysis of the multidimensional barriers which structure access to employment, learning opportunities, leisure and public spaces. Nind and Seale (2009), working with a mixed group of people with learning disabilities, carers, academics and service providers, have attempted to elucidate the concept of

access. They find it problematic, like the concept of inclusion itself, but point out that lack of money, lack of social capital and inequalities in power and access to information all compound these experiences of social exclusion. Without attention to these, community presence is likely to prove ineffective.

5. Conclusion - belonging and becoming

John O'Brien noted that the policies and daily practice of service providers influence:

where a person who depends on services lives, learns, works and plays; what activities fill the person's days; who the person gets to know and where the person belongs; the way the person and others understand who the person is (O'Brien, 1989:5-6).

By focussing on what home and community might mean to people themselves I showed that belonging and becoming, acceptance and inclusion, mattered for each person, whatever their impairment. For example, access to new opportunities and meeting new people mattered for the two young women with profound impairment; having their own home was still an important goal for the two middle-aged women who had been in institutions. This study therefore supports a rights based perspective that access to the means to live a life with dignity has relevance to everyone. The question for services is how to achieve this when, for example, the person takes much longer to form relationships or can pose a risk to themselves or others if they are out and about. My observations therefore are not about whether people should be included in mainstream settings - I take that as a given - but how.

The study showed that the pattern of funding for services, the model of services being commissioned and the skills and expectations of staff structured the opportunities for inclusion. The primary purpose of day centres was to provide care and there were practical and cultural issues in reorienting their services to providing wider opportunities. Staff skills could be insufficiently developed to enable people to acquire independent living skills, even in newer forms of

services. Investment in day services left few resources for flexible, evening support. Not only did this funding pattern fail to delivery equity, with people living in family homes having little access to evening support compared to those in supported living, but it resulted in young people having fewer opportunities to develop the independent living skills or, for people with profound impairments, the relationships, that could improve their quality of life.

For some people, home was their community and a sense of belonging was derived, not from the wider community, but from home or close networks. Family, staff members and provider organisations could be vital links because of their knowledge of the person and their valuing of them. Building on, and learning from, these relationships is fundamental to the process of person-centred planning (Sanderson et al., 1997). Greater investment in flexible support for people living in the family home would pay dividends as it would enable young disabled people to develop wider networks and experience new opportunities. Paid staff could fulfil roles within people's friendship networks and the importance of sustaining such relationships to an individual's wellbeing needs to be acknowledged in order to reduce the losses that people with profound impairments in particular can experience in service settings.

Considerations of home, social networks and community all pointed to the primacy of relationships over location for enabling people's sense of belonging. The individuals in this study required support from another person if they were to participate. On the basis of my study I would argue that, for people with high support needs, belonging and acceptance may be most fully realised in a space where people who know them well are available. Without some strong bonds, it is unlikely that people will have a basis from which to develop looser social ties (Chambers, 2006). This does not mean that people should not have access to new people and new opportunities, indeed many of the participants in my study really enjoyed this, but they needed to have more control over those environments if they were to participate fully in them. Discouraging people with learning disabilities, and especially people with high support needs, from spending time with other people with learning disabilities, or from developing

friendships with support workers, may be counter-productive and produce a form of double jeopardy, robbing them of such social capital as they do possess.

In the next chapter I will report on the views of those commissioning and managing services in order to identify some of the issues that impacted on the experiences of individuals and families.

CHAPTER SEVEN Strategic Planning for Inclusion: Costs and Capacity

1. Introduction

In this chapter I report on the survey of those responsible for the strategic planning of learning disability services in local authorities, the people who would have the responsibility for leading on the implementation of ‘The same as you?’ at the local level. I examine how the interviews explain the background to the individual experiences identified in the case studies and how they foreshadow subsequent implementation issues. I argue that the survey responses represent a struggle over the meaning of inclusion in adult learning disability services, a struggle that influenced the options considered, and the choices made. Fischer (2003) has argued that analysts of policy discourse should consider how struggles over symbols and categories in the policy process shape particular policy outcomes. In this chapter I approach the issue of greater inclusion for people with high support needs as one such struggle and as a challenge to the capacity of service systems, specifically the capacity to shape services to reflect policy intentions.

In relatively informal interviews, the respondents elaborated on their philosophy and whether they thought that inclusion was possible for everyone (see Appendix 14 for the Topic Guide). I first consider the interviews as discourses on inclusion. The ways in which the respondents framed their priorities and described the people at whom their plans and services were targeted represent further ways of constituting disabled subjects (Tremain, 2005: 6) and therefore of exercising the power to include or exclude. Northway (1997) describes an inclusion approach as a game-changing scenario, where the factors that exclude people are challenged, whereas an integration approach proposes integration into mainstream society under the same conditions as those for non-disabled people. Inclusion therefore will require social change on the basis of comprehensive civil rights and the participation of disabled people in democratic decision-making, while integration is ‘akin to joining a game after the rules have

been set' (Northway, 1997:162). Amongst these interviewees I distinguish two different approaches to the inclusion of people with high support needs. One perspective was based on the belief that there should be a presumption that everyone should be included in community living, whereas another position held that inclusion might be feasible only up to a certain level of need and that the ideal of inclusion could only be approached gradually, as the capacity became available to achieve it.

The interviews also elaborated on the perceived constraints in developing services, particularly for people with high support needs. I consider to what extent these constraints may explain the circumstances that were reflected in the experiences of individuals in the study, such as the difficulty of accessing resources to meet an identified need. There were differences between local authorities in terms of the infrastructure of services across Scotland, the nature of the area and population profile and relationships with key planning partners. These differences go some way to explaining why developments could be at different stages in authorities across Scotland, and why developments were occurring at different rates, even on similar issues.

Finally, I continue to develop the theme of 'high support needs' as an emergent needs claim. In Chapter Five I considered how claims for resources were made for, and their consequences experienced by, individuals, and in this chapter I look at how local strategists and managers with a service-wide responsibility in the local authority viewed the emergence of 'new' needs into their planning requirements and budgets. The tension between attempting to implement a more inclusive approach for people with learning disabilities on the one hand, and accessing resources and specialist skills to support some people on the other, emerged as a theme throughout the interviews. I consider how the emergence of Learning Disability, and within that high support needs, as a claim on the responsibilities of local authorities created a challenge to existing priorities for resources and impacted on relationships between planning partners locally. Torgerson (2007:3) contends that the technocratic aspects of policy discourses cannot be taken at face value, but rather are of interest because of how they encode and define who can take part in the debate and what terms of debate are legitimate. I argue that the interviews indicate that Learning

Disability was emerging as a political, rather than a purely professional, issue and that this is significant for the subsequent implementation of 'The same as you?' from 2000 onwards, when decisions about priorities would continue to be contested and change would have to be negotiated between different sets of stakeholders.

Chapter Three described the methodology of the survey, which was conducted by telephone interviews which were recorded and transcribed. The most common posts held by respondents were Head of Adult Services and Principal Officer, Community Care (or Planning and Development). The community care lead would normally cover all adult services - older people, physical and sensory impairment, mental health and perhaps substance abuse - as well as learning disability. The survey was conducted at the time of the Learning Disability Review in Scotland which resulted in the publication of 'The same as you?' (Scottish Executive, 2000). Appendix 15 lists the authorities where interviews were achieved and each interview transcript is indicated in the text by a unique number; however, the local authorities are not linked to the interview transcript codes as respondents spoke very freely under conditions of confidentiality.

2. Underpinning philosophies and approaches

I asked respondents about the philosophy or approach underlying their service developments for people with learning disabilities, and I also sought to find out whether they saw any limits to inclusion in the community, by asking 'whether you think that life in the community is a possibility for anyone or are there certain reasons why life in the community would not be feasible?' (Appendix 14). I was hoping to draw out both their intentions and how practical a proposition they felt a comprehensive community-based service to be.

Half the respondents (14) identified with the language of social inclusion, but what they meant by this could vary and inclusion was not necessarily sharply distinguished from 'ordinary life' principles. For example one person said that

their philosophy was ‘I think a combination of social inclusion and ordinary life, O’Brien’s five principles and the basic principles of normalisation’ (Policy Transcript 8, p. 11). Another reflected that:

first of all about social inclusion ... which in synopsis form we’d simply refer to as enabling people with learning disabilities to share ordinary places with ordinary people doing ordinary things ... that’s just basically about basic citizenship that we’re looking at ... (Policy Transcript 20, p. 5-6).

Amongst those who broadly adhered to a philosophy of including people in the community it is possible to distinguish a smaller group who had a very strongly inclusive approach. The characteristics of this position were: a presumption that everyone should be included, regardless of their level of need, until and unless it proved impossible and the conviction that there should not be a separate philosophy or model of service for one group, even if they might need additional or different supports to be included. I describe this as the ‘all means all’ approach and its proponents as ‘challengers’ because they identified it as their task to change resources and services to make a more included life possible for those who would otherwise remain excluded. For example: ‘social inclusion for everybody. Limits are about what we can do as services, not to be understood as limitations to people’s capacity for social inclusion’ (Policy Transcript 13, p. 12), ‘the assumption would be that anybody can live in the community unless they prove to us that they can’t’ (Policy Transcript 1, p. 5), ‘it’s about supporting people within their own communities, I mean, certainly our principle is, you know, everybody is able to live in the community’ (Policy Transcript 19, p. 13), or ‘our view is anyone can and should be able to live in the community as long as the supports are right’ (Policy Transcript 9, p. 9).

Some of these respondents employed the language of citizenship and rights, for example:

But it is about giving everybody the same right of citizenship and access to services. That includes tenancies, that it is inclusive and embedded in the community...

(Are there any people for whom, whether you think it’s appropriate according to need or because of constraints, that you would think you can’t deliver that model for?)

No ... I think there are issues about, but our view would be that we would push to see everyone in the community (Policy Transcript 3, pp. 3-4).

Among the implications of this view were that services should be planned for a continuum of supports to meet a whole range of needs, for example: 'we haven't separated out, we're talking about people with learning disabilities across the whole range of needs' (Policy Transcript 15, p. 4), 'we just try and see people as people' (Policy Transcript 20, p. 8) and:

... our philosophy would be one that, regardless of the level of disability, people have exactly the same needs. And we would not wish to exclude people from exactly the same range of opportunities as people who are labelled as having less complex disabilities (Policy Transcript 5, pp. 1-2).

In [name of council] what we've felt is that we didn't particularly want to term people as having challenging behaviour or very high complex needs but that we would just try to provide services for those people as we do with any other people and what we'd probably need to do would be to jointly commission the services (Policy Transcript 9, p. 3).

It also followed that there should not be a different service model for some people. For example, 'But the model isn't about a different model of service for people who have high support need from people who have low support need' (Policy Transcript 1, p. 4). In practice this meant that there was not seen to be a requirement for a high proportion of continuing care beds and that the numbers of people considered as needing specialist support would be small. The emphasis would be not on changing people, but on improving the capacity of services and society to be inclusive:

That would be the kind of direction I would like to see [from the national Review]. If the focus is taken away from disabling the disabled to 'abling' the current structures (Policy Transcript 5, p. 24).

Thus there was a presumption of mainstream: 'you look at the mainstream and if you have to you work back from there and say well, look what do we need to do to make sure that this person can live as full a life as possible within the so-called mainstream of society', (Policy Transcript 13, p. 12). Another respondent took up the same point: it would have been better to start changing services by considering those with the highest needs:

And you know if I had to do it again I would start the other way round. I would start with the more complex, high support needs people ... because I think the learning from that and the difficulties experienced makes life a lot easier further up the road (Policy Transcript 22, p. 4).

However an inclusive stance did not equate with assuming that everyone's need could be met by generic services. On the contrary, being able to engineer partnerships that assured access to specialist support, especially specialist health support, was often decisive in enabling some people to avoid being admitted to, or remaining in, institutional care. Access to specialist health support was particularly important to enable people with behaviours that challenged to remain in the community. However the goal would still be to enable inclusion as far or as long as was feasible.

I wouldn't want to develop a separate strategy in any shape or form for people with high needs. The modus operandi needs to be the same no matter the level of support that you require. All we would say is that the more support you require, the more thought - no those are the wrong words - the more specialist input that you may need to get the supports that you require matched to what you need (Policy Transcript 1, p. 4).

One view therefore was that it was an obligation on services to try to make inclusion feasible and that there should be a presumption in favour of inclusion. Another perspective that could be distinguished was that inclusion should be pursued as far as was feasible, but that limits might have to be accepted. I characterise this position as 'not yet' and those who espoused it as 'gradualists' because they considered that inclusion had to be moved towards gradually, as skills and resources allowed. More inclusive strategies for people with high support needs was a goal to be worked towards, rather than a starting-point for change. For example, 'I'd imagine that change is going to be gradual, not just overnight' (Policy Transcript 12, p. 2). One authority was having difficulty moving towards more individualised living arrangements for people with high support needs because all their accommodation still had to be registered:

You can't deal with all the problems at once - that was the way it was in the eighties that people would be in registered accommodation. We can start now shifting, it doesn't mean that we've got to change everything at once. We can start moving slowly by offering a different model of care to people with high support needs (Policy Transcript 21, p. 9).

These respondents could still be making changes to bring about greater inclusion, but they tended to see their goal more in terms of making life as ordinary as possible for as many people as possible. For example,

I mean it is very much the basis of integration and inclusion to enable people to have as normal a life as possible within the community and small groups, you know, a normal living situation to enable them to access the kind of resources and facilities that best meet their needs and to help them develop the kind of abilities they have (Policy Transcript 7, p. 6).

In another authority a care package for a person with complex physical needs had just been discussed that was likely to cost £80,000 a year, while the amount of resource transfer in that area was £29,000. So the interviewee commented that ‘there is a point at which, unfortunately, we will have to be saying, ‘is it affordable?’’ (Policy Transcript 4, p. 7). Others saw the possibility of limits being reached in the future, for example,

In terms of what is the cost limit we’re going to be heading that way because we’re getting some needs coming forward that are really challenging our budgets and there is an increasing tension between what you can ring fence for learning disabilities and what you can achieve for older people (Policy Transcript 21, p. 11).

One council had such serious financial problems that, although it was still the council’s policy to offer individual tenancies, the interviewee felt that these now represented an outdated model of service.

So although the [community] care plan says this is what we’re working for, we’ve been there, we’ve done that and we’re actually coming out the other side and we need to relook at what we’re doing and that realistically we need to look at small group homes (Policy Transcript 18, p. 6).

A consequence of the position that the penetration of inclusion was dependent on the resource available was that it might be necessary to accept that some people would receive a different model of service: ‘Probably for us ordinary living is the best approach, but there will be times when specialist resources are required’ (Policy Transcript 6, p.14), and again

My proposal is that we move to a much more individualised form of housing. As near as we can to single tenancies for people, but recognising that the cost equation doesn’t always work that way. People with higher or more complex needs might need smaller units. Maybe 3 or 4 people in them. (Policy Transcript 2, p. 3).

In conclusion, the apparent consensus that inclusion was the goal of services, masked a difference between those who saw it as an obligation to provide inclusion if at all possible and those who, whilst committed to ordinary life approaches, accepted that some people might be too expensive or have needs that were too specialist to be met by the services the local authority could provide or commission. The former respondents corresponded most closely to the 'developers' identified by Mansell who, 'seek to provide local services which really do address individual needs, and therefore give higher priority to funding services which, with more staff and more training and more management input, are more expensive than ordinary community services' (Department of Health, 2007a: 12). Only this approach is likely to make the case for the higher expenditure required to achieve better outcomes.

The Mansell reports have reiterated that effective responses to people who challenge services are not achieved through different models of service, but rather by organising more skilled support to meet individual needs (Department of Health, 1993, Department of Health, 2007a:15). My interviews showed that there was an important struggle underway in interpreting how to achieve inclusion and that the issues of effective support for people with high support needs threw this into sharp relief. A commitment to try to meet everyone's needs through non-institutional settings, which I have described as a presumption for inclusion, led local planners to consider that services should provide a continuum of supports for a range of needs and that individualised solutions would be needed. Those who saw inclusion as a more bounded possibility, limited by available resources, were more likely to identify different service models for people with high support needs. The second position could imply that some people were beyond the capacity of existing services to provide for, a situation which had been reflected in the individual case studies in this research.

These differences in approaches to inclusion highlight an interesting relationship between inclusive stances and the use of specialist services. From the 'all means all' perspective, a fully inclusive local service requires the development of specialist supports. This is counter-intuitive to those who see specialist

services as synonymous with segregation, and inclusion as aligned with entirely generic approaches. However I have argued that a position in which the capacity of generic services remains unchallenged is more likely to lead to exclusions and to the conclusion that some people should be treated differently. A presumption of inclusion suggests that specialist services and skills should be reoriented to meet needs in an individualised way, rather than used to create separate models of services for people that other services cannot support, a view advocated by Mansell (Department of Health, 2007a:15).

An ‘all means all’ approach determines that specialist resources should be put to use to ensure inclusion for people who might otherwise be excluded; the risk in a ‘not yet’ approach is either that those resources may never be developed or, that they may not be redirected towards safeguarding the human rights of people with high support needs, but instead are used to provide residual or segregated services. Seeking to achieve inclusion for people with high support needs might therefore be predicted as likely to lever greater system change than only extending ‘ordinary life’ approaches for the people with learning disabilities deemed competent to benefit from them.

3. Service development: constraints, capacity and policy learning

The last section considered differences in the philosophy and interpretation of inclusion that might affect the way that approaches to people with high support needs were tackled in local strategies. The interviews also covered the circumstances that interviewees perceived as affecting their capacity to translate their values and national and local policies into service developments that would meet needs locally. In this section I will explore how local priorities and the perceived constraints in bringing about change in services impacted on the possibilities for improving services for people with high support needs. I will also draw out the relationship between some of these constraints and the issues identified in the case studies. The survey illustrates some of the macro factors that contributed to creating the situations that individuals and families

experienced. Some interviews also provided examples of solutions in tackling barriers and constraints to service developments and I will consider whether there is policy learning from these that can be applied to the continuing implementation of the goals of 'The same as you?'.

3.1. Money

Inability to access resources to respond to a crisis or to offer flexible support was one of the problems identified in the case studies, for example when the area team supporting a vulnerable young woman (Tracey) were unable to get approval for her package of care. The survey highlighted underfunding and the problems in freeing up resources from existing spending commitments, as a priority issue. Money was top of the list when I asked commissioners about the hurdles or challenges that they expected to face in commissioning or developing services for people with high support needs and their comments illustrate the limitations that were experienced in the case studies at the delivery end of services:

The main problem we have is that we haven't got any money ... on the whole for the last four years I've been saying no can't do it and if you get someone coming along who has high care needs, we're stuck (Policy Transcript 18, pp 2-3).

The resource problem was also viewed as the most common issue on which local authorities wanted a response from Government as part of the Learning Disability Review. 'Money' was a shorthand response to cover many resource issues that affected the capacity of local authorities to develop services in the community which were appropriate and would support people with complex needs. In particular, local planners hoped for bridging funds to assist the transition from buildings-based services.

The main issue, the biggest problem we see is bridging, basically it's simplistic to say its money. We obviously have quite a bit of money tied up in terms of the of the resource transfer, but that doesn't enable change to existing resources and to change existing resources we obviously require some sort of bridging finance or some sort of facility to enable that change, while keeping the resource going until the change has happened (Policy Transcript 19, p .3).

If resources were a challenge in general, there were specific problems in being able to access the level of resource required for someone with high support needs:

It's the sheer numbers of staff. It's staff time, Lisa. It's as simple as that, it's a basic equation, it's staff costs that rise. It also affects the way we are able to marry-up housing benefit and other kind of support costs and to support people. The equation doesn't work terribly well in terms of higher needs at this stage (Policy Transcript 2, pp. 3-5).

These responses go some way to explain the circumstances that could lead to some of the situations encountered in the case studies in which, despite needs being identified as significant or even urgent, there appeared to be no flexibility to provide or resource an appropriate service.

3.2. Inherited patterns of services

The case studies had also illustrated some of the problems of trying to meet high support needs through traditional day centres. Although additional staffing was generally provided for needs caused by physical dependency, it proved far harder to allocate staff flexibly to provide additional support to people with mental health problems or challenging behaviour. The survey showed the difficulties that local authorities faced in attempting to change day centres into day opportunities that could better meet the needs of people with complex health needs or challenging behaviour. These included the need to disinvest in existing services.

and you know one of my concerns, is that social work tends to be seen as the lead for learning disability services as opposed to the council for agencies across the board. So that you know we spend a lot of money and invest in developing a particular centre unit to ensure that it meets the needs of people with very complex physical needs, but then if you're looking at doing things in the community that becomes a difficulty and that means you then get stuck with that model that re-enforces the lack of integration basically (Policy Transcript 15, pp. 5-6).

Whilst dealing with the inherited pattern of resources was a common issue, there were differences between authorities in the level of existing

infrastructure. One determinant was the way services had developed within the Regional structure of local government before 1996, which left some new district councils having to build up their infrastructure of community services from a very low base.

As it happens, when we desegregated here, we ended up with one day centre that really had people with very sort of moderate or even in some cases quite minimal needs and it was a fairly traditional day centre and that was really only the only resource that we have in this area (Policy Transcript 4, p.3).

In remote rural and island areas, distance created particular issues for service provision; distance and low population density could make it harder to access trained staff and could mean that specialist services were underdeveloped because of a history of people being sent out of the area because of the absence of a local hospital or specialist facility: 'You've got a very mixed bag of roads as well as distance... it's not a conventional urban 20 odd miles' (Policy Transcript 10, pp. 4-5). In a small authority there could be insufficient numbers of people to make the development of a specialist service feasible.

'The same as you?' would be introduced into a context of wide variations in infrastructure across the country which would affect the capacity of local services to respond to policy intentions. The differences included how previous investment in services had been made, the pattern of services that resulted from local government reorganisation, geography and population density and relationships with health partners and with providers. All these factors would affect the extent to which local managers could engineer more flexible responses to need. The next section will consider specifically the issue of partnerships and the impact of these on available skills.

3.3. Partnerships

Some of the individuals in the case studies were still in a long-stay hospital setting because suitable discharge arrangements had yet to be agreed and there was doubt as to whether community services were sufficiently robust to offer support. In the survey, lack of a shared understanding with other community

care planning partners, in particular health services, of the philosophy which the social work department was trying to implement, was cited as a significant barrier to supporting people with high support needs. A lack of shared understanding between partner organisations was particularly important in changing the model of care for the resettlement of people with challenging behaviour. If people had been living in hospital, one of the issues for social care commissioners was getting the agreement of hospital-based specialists that community living was appropriate. This, in addition to the resource and skill issues, could partly explain why some people remain 'entrapped' in long-stay hospitals, awaiting their discharge into the community, a situation encountered in the case studies.

The biggest challenge, the care providers tell me would be those individuals and it is people who are either very, very challenging in their behaviour or who have mental health problems. And I would think one of the biggest challenges really is, health and other professionals coming together and actually agreeing (a) that people with those kind of needs, could live outwith the hospital setting and (b) what kind of support would they need in order to succeed (Policy Transcript 28, pp. 1-2).

Different expectations between health and social work commissioners were evident in one area where total closure of the hospital was envisaged, but at the time of interview there were still 20 individuals described as having 'very high health needs' for whom discharge had not yet been agreed. Health professionals were said to consider that any new support arrangements would have to include a nurse present at all times, whereas social work commissioners thought that this was unrealistic and reflected the fact that the health board did not have to be accountable as budget holders.

We would say we can provide the Escort service, we can't provide the Rolls Royce service, but we hope we never provide the clapped out Mini service. Whereas I think Health are aiming for the Rolls Royce, and we've always had to try and maintain realism in that, okay, but if you get a Rolls Royce service for Jo Bloggs, it means Sam Smith's going to get the clapped out Mini service (Policy Transcript 18, p. 15).

The expectations of the education department within the local authority could also be seen to conflict with those of social work and undermine attempts to commission appropriate services locally.

I think we're certainly getting better now in terms of having the right people round the right tables but I think we're still a long way off

from truly jointly commissioning things because, well, some people are better at it than others, but we're in situations for example, for children and young people where the education department has a very significant role and they're traditionally not good at coming out of their own wee box, particularly when it comes to it, ... for example if we're looking at a young person where their educational needs cannot be met in [name of the council area] then education at the drop of a hat very often will pay £25,000 a year towards the cost of a mainland residential school and we would contribute towards the care costs of that, but they're not yet good at looking at the individual and what we can build around the individual and to try and keep them within the local community (Policy Transcript 13, p. 18).

Another key limitation on the service infrastructure to support people with high needs was the underdevelopment or lack of access to specialist health support.

At the same time I don't think there's necessarily the infrastructure in terms of the health skills. There's a community learning disability team but there's not a crisis team. They're looking at possibly setting up an outreach service to try and work more intensively with people, but that is subject to funding difficulties, ... there's not money in the pot, there's not historically a lot of money that has helped us build up robust services and also there is the issues between health and social work in terms of jointly providing an infrastructure that really supports services where people are very challenging. (Policy Transcript 21, p. 5).

Whether there was agreement on the direction of travel between planning partners including social work, health partners, education and providers could therefore have a direct impact on the capacity to commission appropriate services and to provide the expertise to enable someone to live in the community. In the next section I will consider examples where some of these issues had been tackled and the strategies that interviewees thought were needed to enable inclusion. These examples demonstrate the possibilities for doing things differently and for learning from the experiences in some areas.

3.4. Leading change

Faced with a set of services that no longer met needs, interviewees described a range of strategies that were being adopted to bring about change. One could be described as a rational planning approach, in which the first step was to collect

systematic information about needs and then consider the changes to services that would meet these. A second approach, influenced by ideas of best value, was to review an area of service provision and consider its cost effectiveness and alternatives that might give better value. A more radical approach was to let individual needs determine the future service requirements.

The other thing on social inclusion... is that we're just in the middle of reproviding our largest hostel for people with learning disabilities which has got 20 people in it. We've just in fact completed the person-centred plans, so we're now looking at the new service configuration that will be following this person-centred approach. We didn't start off with the process saying we're going to close that hostel and this is what we're going to put in its place, we said we want to reprovide and we'll base it on a person-centred approach and the outcome of that will determine what the future shape of the service will be (Policy Transcript 20, pp. 4-5).

Joint commissioning was one way in which it was felt that more individualised and appropriate services could be developed. The idea of 'joint commissioning' involved not just pooling resources but also sharing expertise and developing relationships with relevant partners, as these two examples illustrate.

Maybe buy in or jointly commission services between other councils, really with the desire to try and give carers and users of their services some locally based services. I'm very keen to make sure that whatever we do in commissioning we commission to the best advantage of the individual we're commissioning for, and if his or her desire is to live near mum and dad I don't want to go into partnership with [names of authorities in different parts of the country] (Policy Transcript 14, p. 2).

And in the context of high support need, I suspect there will be a need for some specialist commissioning around that client group.... That commissioning exercise is a developmental process. It is a partnership process. It involves providers as much as it involves commissioners. It needs users and carers actively engaged with the process (Policy Transcript 1, pp. 8-9).

Whilst joint commissioning was seen as a way of influencing services strategically, the development of assessment and care management was identified as a way of trying to create different expectations within services. In one authority, area-based care management was presented as a real opportunity to develop support packages that linked into opportunities in the local area (Policy Transcript 1, p. 10). In another, money from hospital closure had been reinvested to strengthen the capacity of the service to respond in this way.

We've invested some money in assessment and care management teams because I'm very conscious of the needs of older carers who are critically worried about what happens to their sons and daughters if they die tomorrow. I'm trying to have a tight focus on them, and also a focus on young people coming through Future Needs. (Policy Transcript 2, p. 9).

I mean one of the issues which I do hope the Scottish review will address is the whole issue around assessment and care management and how we're going manage to educate the assessors and the social workers to get away from the assumption that somebody automatically has to go into a day service when they leave school (Policy Transcript 19, pp. 4-5).

Another issue identified through the case studies was the management of risk. From the survey there were successful examples of risk being successfully managed in the community. For example one authority had commissioned a project for people with complex disabilities in 1996. This included one woman who had been sectioned and frequently ran in front of cars. The interviewee reported that she now successfully lived in her own house on the main street. Another had found that multidisciplinary working had enabled the authority to maintain people in the community, while minimising the risk to other people.

We actually do have a number of people who without adequate supervision could present a risk to the community, and what we're having to do is work closely with the psychiatrist, psychologists and the police. We have regular case discussions looking at strategies to help people adjust ... and it's more about modifying the environment for some people as opposed to changing the person's approach (Policy Transcript 6, p. 7).

There was general agreement in the interviews that opportunities for inclusion were fewer for people with high support needs. In one area access to additional funding for a sessional budget had made a difference.

Obviously in terms of getting people physically out of centres so that centres become just a base, I mean you're dependent on staff, and actually quite a lot of staff, and I think there are issues there around you need a skill mix, different levels of staff and some flexibility. (Policy transcript 19, p. 5).

One solution to the problem of lack of local experience and skills was to network with sources of expertise in other areas of Scotland.

So it's been a major learning experience for us, and we've had to pull in, you know, help from all areas over Scotland, we've found lots of training from people, you know, from St Andrews University, we've

gone and visited many placements on the mainland, to see if we are on the right tracks and we've built up quite good links with some of those people. So that has helped, but of course being geographically isolated, it's been difficult for us and we're still finding it difficult, you know to get the proper support and most appropriate forms of training (Policy Transcript 24, p.3).

In this respect the Review's recommendation to set up a national centre for learning disability (SCLD) was seen as an important way to support authorities, share information and expertise and encourage consistency across Scotland.

3.5. Conclusion

Expectations of bridging monies to ease the transition from buildings-based day services were not to be fulfilled by 'The same as you?', although a change fund of £36 million over the first three years was made available. Nor was the development of more specialist care management a strategy favoured by the national policy. However person-centred needs assessment did become a recommendation, and improvements in commissioning processes and skills remain a well-supported strategy for improving outcomes (Campbell, 2007).

Key barriers to implementing changes, according to the survey, included underfunding and inflexible resources, lack of access to specialist health skills and variations and gaps in the infrastructure of community services. Underlying many of these issues was the lack of integration between local authority social work services and NHS partners, health boards and NHS trusts. The lack of an agreed approach between health and social work may help to explain how the case studies found people with high levels of needs could have unresourced packages or remain 'entrapped' in long-stay hospitals without appropriate services in the community.

The interviews suggest that more integrated services and the development of comprehensive specialist health support would be essential to the effective implementation of 'The same as you?' for people with high support needs. 'The same as you?' was not seen everywhere as a policy for health as well as social

work services, although it was intended to be, and the message of inclusion and the development of mainstream resources has overshadowed what it had to say about the development of specialist supports. These interviews suggest that until these issues are addressed, and there is a shared vision across health and social work services and other partners, people with high support needs may remain at risk of entry to institutional settings and be seen as too difficult and costly to receive local support.

4. The emergence of new publics

Previous sections of this Chapter have considered the philosophical and practical issues that affected the development of services. In this section I put the survey in a slightly broader context and place it in time within the development of social care policy. The emergence of Learning Disability as a specific area within local authority adult services, and the particular issues posed by people with high support needs, meant that planners were confronting new problems which were emerging as a public agenda. I argue that this represents another kind of transition, in which learning disability services become a public and political issue as well as a professional concern. All these tensions have relevance for understanding the issues that have influenced the implementation of 'The same as you?'.

Newman has analysed the instabilities that were affecting welfare policies at a time when liberal views of the equivalence of the state and the public sphere were being challenged by 'new publics', creating conflicts which had to be managed by public service bureaucrats (2007). The interviews in this study showed local authority planners grappling to manage new demands, engaged with the democratic control of councils while at same time trying to modernise their services.

Planning specifically for learning disability services was at a transitional point between generic community care planning and emergent strategies for

particular groups. At the time of the survey, the main local framework for planning services for people with learning disabilities in Scotland was the community care plan. The Joint Community Care Plan provided the planning framework in most areas; 12 of the 28 were working only to this. In at least eight of the local authorities a discernible process was underway to develop a specific learning disability strategy, either through joint working groups and/or consultation with people who used services and carers. The Learning Disability Review was to make the expectation of a specific plan much clearer.

our action plan for learning disabilities is in itself quite detailed. We do not have a strategy per se for learning disabilities for the moment but what we do have is a number of things beginning to fall into place that will inform a strategy (Policy Transcript 1, p. 1).

This situation was also reflected in the relative lack of information about the numbers and needs of people with learning disabilities to inform planning; the Learning Disability Review was to have to rely on prevalence data. One authority which covered a remote and rural area was establishing a multi-agency database for this reason.

I mean in terms of people living in the community we don't have terribly good information. We do know that we have people living in quite remote areas ...who have been supported by family and very little else (Policy Transcript 13, p. 2)

At the same time as community care was providing an overarching framework for the development of service plans for adults, joint planning between social work departments and health boards was developing, albeit at different rates, to respond to the closure of long-stay hospitals. Some respondents in local authorities saw the development of joint plans as positive, but to others the parallel process was not unproblematic. The local authority plan could be seen as a more strategic framework and was subject to democratic decision-making, whereas the joint plan might actually be driven primarily by the health board because they held the resources, and was apparently not always fully owned by local authority respondents. For example, 'we've apparently signed up to the [name of health board] strategy for the [name of part of local authority area] end' (Policy Transcript 22, p. 2) or,

our main planning document is of course the community care plan and that provides an overview of where we see strategic and other development in relation to all our services and our discussions, just

now there's obviously a chapter in relation to learning disability ... Now in terms of Learning Disability Strategy there is also, you may come across when you're speaking to health or other people in social work, they may refer to the [name of health board] learning disability strategy. Now what that means is something quite different, that relates to a specific hospital closure programme - reprovisioning ... referred to by health in particular as the learning disability strategy, whereas actually the strategy is the community care plan (Policy Transcript 20, pp. 1-3).

do you know what I mean, the reality is there is no joining of the budget etc so in practice it's really the health strategy that it is termed the joint learning disability strategy between the council and [name of health board] (Policy Transcript 10, p. 1).

In their study of plans for hospital closure, conducted in 1997, Stalker and Hunter reported a lack of clear resettlement plans and targets (1999:191). Some progress seems to be apparent in this survey, but the interviews also indicate that the finance, planning and partnerships around resettlement were, ironically, not necessarily fully integrated into community care planning, which may have resulted in a weakening of strategic focus.

The main priorities evident in the community care planning for adult learning disability services reflected the agenda of modernising services to respond better to need, with day services, the main element in local authority provision, featuring as the main focus of service modernisation. Restructuring day services emerged as a major priority (mentioned in 14 of the 18 councils in which it was possible to identify priorities) and hospital resettlement was identified by nine respondents.

New pressures were affecting service plans. The kinds of people whose needs most challenged planners were those identified in the case studies: people with high physical or complex health needs; people with very challenging behaviour and/or a dual diagnosis of learning disability and mental health problems and offenders. People with autism spectrum disorders were particularly identified as not having their needs met by existing services. Both in terms of hospital resettlement and within the community, there was a sense that commissioners now had to grapple with some types of need that were more complex than they had faced hitherto. 'New' needs were challenging existing service models which were being found wanting.

Now when this model [of day service] was first planned for it was appropriate because of the numbers that were identified several years previously. However it's no longer appropriate because we have two very distinct groups. We have people with profound and complex needs with severe physical and medical needs and people with challenging behaviour with Autism and the two groups were placed within the same unit initially (Policy Transcript 8, pp. 3-5).

There were a number of directions from which pressures were being exerted to respond differently. One was hospital resettlement which could result in some areas in people with higher levels of need, and specifically health needs, requiring a service when there had previously been no provision for these levels or types of needs. A further pressure was the emergent needs of more children with increasingly complex needs who would require adult services:

We are actually very aware, from the work that we are doing with our colleagues in Children and Families Team, the Future Needs stage. The needs of young people coming through education now are much more complex in the main. Or there is a higher number of people, young people, with complex needs coming to the attention. And we've profiled that again and we reckon that this year and next year the cost to the Council could be £1/4M in care costs. For these young people coming through. So the major issues for us now, Lisa, are how we manage that (Policy Transcript 2, pp. 7-8).

The scale of changes needed meant that service commissioners found themselves having to engage with a range of new publics, carers, people who used services and in some cases, the general public also. Arguing for different services for people with learning disabilities meant convincing a number of constituencies that the changes were for the better. Individuals and carers might themselves have attachments to the services they were used to, and local councilors, who would ultimately make the budgetary decisions, had to be reckoned with. However the interviews showed that some local authorities were engaging enthusiastically in new relationships with people who used their services.

..when you're talking about traditional forms of services you're talking about people having very narrow and limited views as a result of having received or having provided that service and therefore there is a major change agenda for service users, for carers and for staff (Policy Transcript 15, pp. 5-6).

We are seeing evidence of carers, some of whom we had quite a battle with in the early days to get people out of the day centre and into more open environments, and carers who've now had the

experience of what it's been like for them and what it's been like for their dependant relatives saying, you know, one thing you'd better do is make sure that the funding for this project doesn't go down the plug hole... Now you know that's coming from the very people who a few years ago were saying, no we're not agreeing to this (Policy Transcript 13, p. 8).

The interviewees were not the ultimate decision-makers in local government; the councilors were. One very experienced local government officer explained how important a strategic steer from national government was in order to try and win the argument with local councilors for newer forms of services.

Because I think at officer level we need to take our political masters with us. And I think strong messages from the centre about social inclusion and ordinary living would help us. Members like bricks and mortar. They like buildings that they can go to see people in and so on, despite their quality and so on. And I think we need a strong push from the centre to say 'No, the agenda needs to shift here, we can't go on ware-housing people like we do' (Policy Transcript 2, p. 25).

In another authority there had been significant consultation and involvement in the development of the local strategy.

That process culminated last month in three large Stakeholder Conferences in three parts of [name of council area] where there were over 250 people attending. And from those three conferences came seven major themes and, as we speak, service users, carers and other staff are writing the seven chapters of the document (Policy Transcript 5, p.3-4).

Officials in another authority had sought to evaluate and then improve the information available to people with learning disabilities so they would be in a position to contribute to service development in future.

So we're now presently developing a series of videos which will be part of an information process. People will be empowered to use these when they wish and they'll be at various places, like the libraries and so on and at the same time we are bringing in a consultancy advocacy group to develop citizen advocacy with two groups of people, one a rural group and one in an group within [name of council area] and the idea is that by August there should be some people with that group who'll be able to tell the powers that be what services they want (Policy Transcript 11, pp.1-2).

By the late 1990s the service modernisation agenda within community care had had limited impact on the lives of people with learning disabilities. However this survey showed that specific strategies and local planning partnerships were

emerging under the umbrella of community care before the publication of 'The same as you?' Drivers for change included the realisation that existing services were not meeting needs, hospital resettlement, and growing awareness of needs that local authority services had not met hitherto, especially needs that had previously been catered for primarily by NHS services. Ward and colleagues systematically analysed the Joint Investment Plans produced by English local authorities as a requirement of 'Valuing People' (Department of Health, 2001) and found an absence of information on population, current services and expenditure (2004:16). These interviews indicated that in Scotland also, the information required for planning was sparse and local needs assessment at an early stage of development. A significant impact of the local authority having assumed the lead for planning services under community care, was that the shape of future services for people with learning disabilities had to be approved by local councils and was recognised as a public issue, requiring the active involvement of people who used the service, families, and in some instances, other members of the public. I see these developments as marking a significant stage in the emergence of Learning Disability as a public issue after which expectations of services and conflicts over resources could not be seen as matters of only professional concern. People with high support needs were one of the drivers of these developments; as the costs of their support and the partnerships required to meet their needs could not be contained within existing structures and budgets, the nature of their needs required new approaches from services and the demands they made on systems raised significant issues of equity.

At the same time as the development of needs-led services was beginning to be addressed for people with learning disabilities, resettlement programmes, which were only partially funded in many areas, were putting a strain on the capacity of local services. At the very moment that the skills to support complex health needs were most required to achieve the goals of community care, many local authorities and health partners were in dispute about resources and not in agreement about who could safely be discharged from hospital. Stalker and Hunter (1999:187) found that NHS Trusts were the strongest advocates for continuing hospital care for people with challenging behaviour, dual diagnosis or multiple impairments. 'The same as you?' was to set a general direction of inclusion, with a firm policy that all long-stay hospitals should close and that no

person should have a hospital as their home, whilst maintaining that people should retain access to specialist supports when they needed them. It clearly stated that 'The aim of the specialist service should be to support mainstream services and to help people stay in their own homes as far as possible' (Scottish Executive, 2000:41). However as this survey showed, the values of inclusion were not agreed across all the stakeholders and thus there was no guarantee that resources and skills would be integrated or shared in pursuit of a joint vision. Moreover, debates as to whether they should receive a different model of service continue, despite the completion of the hospital closure programme.

5. Conclusion

Those with responsibility for developing local strategies for learning disability services at the time that 'The same as you?' was being planned and published held different views on the best way to promote inclusion. In section 1 of this Chapter I showed that some believed that local services should be able to meet the needs of everyone in their area and that it was their job to challenge existing systems to make this happen. The service configuration that followed from this view was of a continuum of supports to meet a range of needs. Others were more conscious of the constraints and limitations that affected service development. They envisaged a gradualist approach in which inclusion might 'not yet' be possible and had to wait upon the appropriate level of support being affordable and available. The consequence of this position was that for some people, a different model of service, such as a group living arrangement, continuing care or an out-of-area placement might have to be settled for.

What was particularly interesting about these responses is that neither saw inclusion as meaning the use of mainstream services without any support from specialist services. Those with responsibility for learning disability services within social work were starting to pursue a needs-led agenda and to reshape local authority day services and provision, but in few areas were health and

social work services combined in joint teams and so the scope of 'modernisation' was limited.

The interviews illuminate the factors that created limitations on the capacity of individual social work departments to respond to the needs they faced. Those responsible for learning disability services were facing new challenges that demonstrated that existing models of service would need to change. Needs that challenged the system exposed particular weaknesses: principally, inflexible resources and different degrees of effectiveness in joint working across health and social work services. Many commissioners were tackling the change agenda, but they remained daunted by resource constraints and the dilemma of meeting present needs, while trying to bring about long-term change. In translating aspiration for change into policy implementation they had to contend with local factors such as the pattern of services they inherited and the impact of geography and population density, as well as relationships with providers and other stakeholders. Solutions were emerging in the form of joint commissioning, the use of assessment and care management and person-centred approaches, but these were at a fairly tentative and exploratory stage of development, given the size of the challenges of resource distribution, service design and skills development.

Thus the situations encountered in the case studies could come about. Where there was no room for manoeuvre with budgets, it would be possible for a crisis like that faced by Tracey in her life, to be beyond the capacity of local services to respond to. Where day centres had to balance a wide range of needs and lacked access to flexible, sessional staff, Michael's position of having needs greater than his day service could accommodate, would arise. Where there was not agreement between health and social work commissioners, where care management procedures were not sufficiently robust, where there was insufficient support available from health services and where providers did not have the skills to manage people at risk, Stuart, Sheila and Ailsa might remain in continuing care or face a future of failed community placements. There was a need to share expertise across Scotland in order to develop the processes and

skills needed to avoid people with high support needs being excluded from new forms of support in the community.

Meanwhile, people with learning disabilities, including those with high support needs, were raising new issues for the agenda of local authorities. In turn some local authority managers were embracing the challenge of informing those with an interest in their services about their plans and engaging them in planning for the future. This represented a recognition of public accountability, but it also would raise dilemmas in achieving principled change that might not be acceptable to all the interests involved.

The policy outcome intended by the ‘The same as you?’ was that more people with learning disabilities should live ‘ordinary lives’, while at the same time having access to specialist support when required. This survey showed that many local planners and managers struggled in practice to unify the two parts of this agenda. Many of the challenges identified in these interviews remain current issues for service provision. Agreement that there should be a presumption of inclusion for everyone and that specialist support should be directed towards the support of mainstream services has yet to be achieved. At a time when significant cuts in public expenditure are expected, it might be predicted that attempts will be made to draw lines about the affordability of certain care packages and which needs can be met in the community.

In the next and final Chapter I draw together the overarching themes for the research.

CHAPTER EIGHT Discussion and Conclusions: Rights, justice and participation

1. Introduction

I began this research in response to a claim that I felt had been made upon me as a citizen to understand and challenge the exclusion of some people with learning disabilities from developments towards inclusion. My response to this challenge was through the practice of research. Ten years further on it is incumbent on me to address to what extent my research addressed this challenge, what I learnt as a researcher and the implications of my work for the field as it is today.

This chapter therefore discusses the main themes that have emerged from the research and presents my conclusions on the implications for theory, policy, and future research. Section 2 reviews the main findings from the empirical research. Section 3 draws together the overarching themes from the two parts of the study, the case studies and the policy survey in the light of the themes considered in Chapter One of citizenship, inclusion and social justice. Section 4 comments on the limitations of the research and discusses the implications for research practice with people with high support needs of both my own work and of recent developments in method. Section 4 discusses the implications of my work for commissioning, services for people with high support needs and for future policy developments. Section 5 presents my conclusions.

Three questions were posed at the beginning of this thesis. The first was how people with learning disabilities, who were deemed to have high support needs, experienced inclusion and exclusion in their daily lives. The second was how research could address their experiences and include their understandings of belonging. The third was whether barriers to inclusive and comprehensive services were resulting from the way in which the thinking and policies of

community care were being translated into service developments. A number of premises underlay these questions. These were that the experiences of people with all people with learning disabilities should be able to influence service developments through participation in research, that general lessons about social inclusion and citizenship might usefully be drawn by from a study of people who pushed the capacity of service systems to their limit and that policies and services designed to promote inclusion should be examined for their impact on people who were most likely to remain excluded. Behind this last point was a concern to avoid a new normalcy in which the historical labelling of people with learning disabilities as incapable adults becomes increasingly associated with people who do not conform to any new norms of active citizenship and social inclusion.

I will briefly summarise the matter of the thesis before outlining its overarching themes and considering to what extent I have been able to answer these questions. I will then present my overall conclusions.

2. Summary

Chapter One of this thesis considered ‘The same as you?’ Review of Services from two different perspectives. The first was that of the development of Learning Disability theory and practice, with particular reference to ‘ordinary life’ principles, which I found to have influenced its approach to what constituted a ‘good life’ for people with learning disabilities. The second perspective was that of New Labour policies of equality of opportunities, in which labour force participation is identified as the preferred route to active citizenship. I argued that there were dangers that the capacity of the ‘The same as you?’ to deliver on inclusion would be limited by its being inscribed within this framework. I then considered ‘The same as you?’ and its conception of inclusion within a broader literature on citizenship, focusing particularly on the relationship between inclusion and social justice. I identified the tensions

between ‘sameness and difference’ as an overarching theme that linked writing about Disability with the citizenship literature.

Chapter Two considered the practice of research with people with learning disabilities. Starting with the early interactionist studies associated with Edgerton (1993a), through the life history work of Atkinson and Walmsley (Atkinson, 2004, Walmsley, 2005), and other strands of emergent inclusive research, I considered the challenges of developing research that can both challenge the causes of disablement and be inclusive in its practice. I highlighted the particular barriers of including people deemed not to have capacity to participate in research and I argued that it was the responsibility of researchers to develop their capacity to be inclusive. I cautioned that cognitive capacity should not necessarily be a reason for excluding people from engagement as research subjects because this reinforced a denial of their capacity for meaning-making and contribution.

Chapter Three described the research methodology: how I had conducted my research, the rationale for the choices I had made, and how these had affected the development of the research. I aimed to investigate the experiences of inclusion and exclusion in the daily lives of people who were receiving at least one-to-one support on a twenty-four hour basis, or were deemed to be too challenging to discharge from long-stay hospital. This was in order to explore whether I, as a qualitative researcher with no background in working with people with learning disabilities, could gain an understanding of their social worlds by adapting qualitative research approaches. It was also to consider if the ways in which community care services were being developed created barriers to inclusion that might explain some of the experiences of people that I interviewed.

I used quite different approaches for the two parts of the study: Firstly I conducted 14 case studies in one Scottish city to examine daily experiences of belonging at home, in daily routines and among wider networks; secondly I conducted a telephone interview survey of those with lead responsibility for developing learning disability services in local authorities across Scotland.

In this Methods Chapter I explain how I negotiated issues of consent and participation. In the case studies I found a need to adapt my approach to each individual by using a mixture of interview, observation and interaction, and I came to use my interaction with participants as a focus of the research, and to regard the data as co-produced between the research participants and myself.

Four data chapters followed. In Chapter Four, 'Moving Beyond Categories', I introduced the ways in which the participants in the case studies had made themselves known. I argued that all could make significant contributions and that they challenged labels of incompetence and incapacity by demonstrations of themselves as informants, family members and tradition-bearers. I considered particular issues in communication between us and reported my experience that attentiveness to individual communication was required to overcome the barriers that could be set up in the research encounter. I concluded that relationship as well as technical capacity was important to enabling participation in research. I found that interpreting the experiences of study participants posed as many challenges as obtaining them, and I reflected on my own power in shaping the stories of participants. I concluded that supposed cognitive incapacity should not be a barrier to research participation because the state of incompetence was not fixed, but was a changeable characteristic that could be shared by researcher and researched. Whilst it is important to clarify my role in mediating the accounts of the situations of participants, this should not invalidate them as long as their partial and situational nature is acknowledged.

Chapter Five took up the theme of power within the service system. It looked at how people's needs were categorised and the reasons for which a high level of support was provided. It identified a lack of fairness and that different needs were met by different levels of responses. Two reasons were offered for this. First, that care was seen as primarily a private responsibility and state support was limited to daytime support (when the productive citizen might have been at work) or to substitute for family care. Second, that some reasons for providing additional support, viz. dependency and public protection, were more likely to be seen as funding priorities than issues that caused only private burdens. Moreover

I proposed that my data suggested that it was precisely those aspects, such as communication support, that enabled participation which were least likely to be prioritised.

Having established the rationale for which people were receiving support, I then considered their experiences of social inclusion and exclusion. Chapter Six, 'Being and Belonging at Home and in the Community' explored what home and community might mean for each person and how their inclusion had been enabled or prevented by the places where they lived, the ways they spent their time, and the nature and quality of the relationships that they enjoyed. I discovered that relationships and support were the precondition for their inclusion. Continuity of trusted relationships could make home safe, time meaningful and the community a place to be explored. However meaning, belonging and self-development could also be undermined if the necessary resources were not provided to enable participation.

Finally in Chapter Seven I turned to the survey of those responsible for the strategic planning of learning disability services across Scotland. I found some reasons that explained the situations encountered by the case study participants. For example, lack of planning and inflexibility of resource systems could create situations where it was not possible to respond to needs. A lack of shared vision and agreement between health and social work could stall discharges from long-stay hospitals. Some commissioners believed that there should be a presumption of inclusion for everyone, others that inclusion had limits, but all saw access to specialist supports as essential if everyone was to be included, and this required agreement about the importance of inclusion. Thus issues of both recognition and redistribution were structuring the experiences of people who required services.

3. Main themes

I will now set out four the key themes that I consider to have emerged from this work. These are: the importance of relationship to inclusion; how Disability and dependency is created through the labels of incompetence and incapacity; the relationship between participation and fairness; and, recognition and redistribution. I will address each in turn.

3.1. Relationship and inclusion

My first research question was what inclusion might mean to the people in the study and how this might compare with the aspirations of policymakers and others whose ideas of ‘a good life’ for people with learning disabilities I set out in Table 1.1. I have selected my first theme, the importance of relationships for inclusion, because it was of great significance for the study participants. The protective effect on health of social and community network is also recognised within Scottish policy on health inequalities (Scottish Government, 2008:12).

In Chapter Six I showed how relationships were highly valued by people in this study and how they were essential not only for their wellbeing, but for their care, safety and autonomy. Continuity of relationships enabled people to realise meaning and who they were. This was demonstrable even by people who did not use words. Belonging was expressed in terms of relationships. Stuart felt himself to be part of a community of people who had lived in the long-stay hospital and felt a connection both with those who had died there and those who had moved on. Mairi drew attention to the sense of belonging she had felt in her choir at the day centre. Relationship was not a luxury, but was essential for the study participants to access autonomy, inclusion, good outcomes and rights. Indeed it was important to the realisation of all the seven principles set out by ‘The same as you?’, which were, being valued, contributing to the community, not be bullied, being treated as an individual, being asked about choices and being involved in making them, realising potential and accessing local services. However, all the people in this study depended on others for their inclusion to

be realised and also needed active support from others to make and maintain relationships (see 3.2 below).

Yet, as far as I was able to determine, for most participants, a small number of close relationships were more in evidence than a wider range of looser ties (Granovetter, 1973), a situation which is plausible in the light of other research about people with learning disabilities and more severe impairments, for example, Clement and Bigby (2009). The consequences for their inclusion were significant, and I identified some of the barriers to relationship-building including the lack of opportunity to go out and mix with peers, lack of time to make and sustain connections and negative reactions from others. Building connections outwards was not the main remit of day centre staff, although the purpose of day centres was changing, but I also encountered differences in how well equipped even staff felt to engage with particular individuals.

I used the idea of social capital (Bates and Davis, 2004) to understand the contribution of paid staff to the inclusion of study participants. Phil was one of those who demonstrated to me that particular staff had played a very important role in his life and I would interpret him as telling me that he regarded them as part of his social network. It seems to me, therefore, that any service arrangements or aspirations for greater inclusion that disrupt meaningful relationships that have been formed with staff, or that see staff as interchangeable, or that devalue relationships with staff and do not appreciate their role in bridging to other relationships, further reduce the limited stock of social capital that people may enjoy. Both Ailsa and Marilyn's situations demonstrated a different approach in which support organisations were encouraging staff to share their own families, networks and interests with the person that they were supporting.

Thus relationships were essential to inclusion and it is important to make this point first, so that there can be no ambiguity that this should be taken account of in the purposes for which support is funded, including the extent to which families are supported to be able to sustain themselves, and the way in which staff are expected to understand their roles. However I do not wish to propose the position that relationships with families and staff are sufficient. On the

contrary, I think that the primacy of relationship to people's own understanding of belonging points in a quite different direction. It suggests that, despite the failure of policy and services to date to deliver on this, relationship-building with a wider social network should be at the heart, rather than the periphery of social care development. However such approaches have not been seen as a priority for funding. For example, whereas 'The same as you?' envisaged that local area co-ordinators would become the main support for people with learning disabilities and their families, providing them with information about local resources, personally linking them in to community activities and themselves developing new community groups, nine years on there are only some 75 local area co-ordinators in Scotland, compared with the 500 who would exist if the recommendation of one for every fifty people with learning disabilities had been implemented (Stalker et al., 2008).

Even on the Left of British politics, there is now an analysis that part of the problem is that the welfare state has undermined social relationships between people. Writing in a recent issue of 'Soundings', Hilary Cottam suggests that, 'It is as if the state is investing in making itself not only the provider of solutions but the friend to the elderly. It is a story of relationships in the wrong place' (Cottam, 2009). As an alternative she proposes that the welfare state should be turned on its head, and priority be given to enabling relationships and social networks. Working with older people and their families in Westminster and Southwark, she is experimenting with a model that includes face-to-face support, and investment in building local social networks. This approach has strong resonances with more inclusive approaches within the field of Learning Disability.

Thus in this study, inclusion was experienced through relationship, but not all relationships were empowering. The extent to which relationships could enable inclusion was influenced by the way in which care was funded and delivered and therefore is a concern of policy. Relationship is little emphasised in the dimensions of equality set out in the report of the Equalities Review (Equalities Review, 2007). One way in which the experiences of individuals in this study, and research more generally on people with learning disabilities, should contribute to current debates on social care reform is to stress the fundamental

importance of supporting relationships and social networks in order to achieve the outcomes of better lives to which policy aspires.

3.2. Constituting the label of incompetence

The second theme I identify is how Disability was constituted through power relations and specifically how labels of incapacity and incompetence contributed to experiences of exclusion. In this section therefore I will be referring to the social model of disability, and the extent to which its analysis of the causes of disablement have explanatory value for the situations I described.

This theme draws together the experiences identified in the case studies (Chapters Four to Six) and the analysis of the survey of commissioners (Chapter Seven). I drew on the work of Stone (1984) to consider the uses of the categories into which people were allocated for the purposes of deciding who should receive what level of service and I suggested 'high support needs' operated as a bureaucratic category, effectively a method of justifying the allocation of additional resources, rather than a coherent category of need (Chapter Five). Throughout the history of welfare services, people with learning disabilities have been subject to such categorisation or 'labelling'. As David Race (1995) has shown, such categories have been driven by the concern to decide who should receive which service and have led to the people so designated being ascribed characteristics which are then used to place limits on the degree of inclusion for which they are deemed to be 'fit'.

Residual elements of such an approach seemed to be a risk for people in this study. By designating certain people as having high support needs, services also problematised them. They could be seen as 'other' to mainstream support (Chapter Seven). Commissioners, under pressure with resources, might deem certain groups as beyond the capacity of community services, thus transferring the risk from the service system to the individual. Similar practices were evident in frontline services, as illustrated by the case studies. The categories by which needs were constructed could result in some needs, such as complex

health needs, being ruled out of the scope of services and public participation (Chapter Five). Moreover, if the level of support that an individual needed was denied, and they reacted with challenges, that person could be seen as problematic in both care and public situations and face exclusion from these spaces. For example, it was reported that Tracey was considered to be breaking rules deliberately, on the grounds that she laughed when challenged. As a result she was excluded from services, rather than supported to deal with her problems, which turned out to include a severe and enduring mental health problem. Similar transfers of risk were apparent in Margaret being sent home from the day service when she had a chest infection. The analysis could even perhaps be applied to Sheila, who had been constituted as an offender when she had been discharged to accommodation with insufficient support and hit out in her distress.

I see these situations as examples of a systematic transference of responsibility from services to the individual, particularly, but not exclusively, individuals whose behaviours challenged services. Thus there was a relationship between exclusion and the way Disability was constituted. 'Irresponsible' citizens were created by a limitation of the capacity of the service system to be inclusive. Unruly bodies and unpredictable minds could be seen as beyond the scope of inclusion, and the cost of support only served as further grounds for conditionality and exclusion.

I find the social model of disability helpful in explaining the greater part of this exclusion. The labels assigned to people deemed them to be incompetent and lacking in capacity, rather than serving to highlight the gaps in the services on offer, or the weaknesses in the support with which people were provided. In this sense, therefore, the cause of their disablement lay in the barriers presented by the service system. Moreover, as I illustrated, their alleged identities as risky, vulnerable or disruptive were not fixed characteristics but were malleable according to physical environments and the social situation. For example, Michael's need for a wheelchair was created by the number of people wanting lunch at the same time, not his inability to walk. I also found parallels to these situations in my own research. The capacity of individuals to contribute was affected by my abilities to use the right communication approach.

However, some of the exclusions which occurred are most readily highlighted by reference to impairment effects, even though it is the case that the Disability resulted, not directly from these, but from an inadequate response to them. In particular, unmet health needs, or barely managed health needs, were a significant reason for limitations on people's inclusion. The rhythms of life for Margaret, Jennifer, Michael, Mairi and Anne were profoundly affected by their health needs, which were irregular and unpredictable in their impact. There were organic reasons why Marilyn's mood changed in an instant; the impact could be managed, but her self-harming was not socially constructed. My point is not that the existence of health needs in some way undermines the social model of disability, but that the impact of health needs should be acknowledged as requiring appropriate management. Inadequate access to support for health needs is an important cause of inequality for people with learning disabilities, as this study also showed, and should not be disguised. Part of the problem may be one of identity and categorisation. Health needs featured as a reason for additional support for a number of people in this study; to assume learning disability was their main identity, and that other aspects of their health were additional to that is reductionist. They were also people who lived with long-term health conditions, including mental health problems, as well as being men or women, young or middle-aged.

One way in which it may be possible to theorise the situations described in this section is through the capabilities approach developed by Sen (2009) and adapted by Nussbaum (2006b). The capabilities approach originates from the field of development, and proposes an alternative to systems of value based on either wealth or utility (Nussbaum, 2006b). It allows for people to have different 'goods' to which they ascribe value and also allows for variations in capabilities, that is the set of circumstances that determine their capacity to attain those goods. Such an approach can legitimate providing more resources to some on the grounds of inequalities of capabilities. Where the social model has great power in highlighting where responsibility for removing discrimination should lie, and the exclusions which can result from labelling, the capabilities approach may offer some purchase on the problem of how to justify the uneven allocation of resources to respond to the additional support which some people require to

participate in society. It is to issues of participation and fairness that I now turn.

3.3. Participation and fairness

So far I have considered relationship as a dimension of inclusion, and labelling as a way in which exclusion can be created. The third theme is the relationship between participation, citizenship and fairness. This addresses the issue of the conditions needed to overcome the barriers to accessing rights. I shall argue that participation is essential for accessing the rights of social citizenship, but that this will only contribute to greater fairness if there is access to the particular means that any given group requires to participate. This study has highlighted the fact that needs for support for communication and decision-making may be essential to support some people's participation and this may challenge assumptions of autonomy and independence as a characteristic of citizenship.

The extent to which citizenship rights can provide a safeguard for disabled people, or other marginalised groups, is disputed, as I discussed in Chapter One. Civil rights in particular, it is argued, cannot reduce inequalities unless accompanied by measures to ensure access to social rights. Moreover, the normative notion of the citizen (for example white, male) can reinforce existing power relations. This analysis seems particularly pertinent to the issues discussed in this study. The characteristics of independence of mind, legal competence, and hence cognitive capacity, are hard-wired into Western democratic and legal traditions and institutions. If assumptions of independence and rationality inform concepts of civil rights, even the formulation of procedures designed to achieve equality and fairness will be exclusionary. Moreover these problems are not necessarily overcome by newer formulations of democratic theory, such as deliberative democracy, however appealing these may at first appear. Weinberg (2007) has analysed the standards of competence which Habermas demands for rights-bearing participants, and he concludes that these are necessarily exclusive of many people with learning

disabilities because they set too high a bar of communicative (including interpretative) competence and treat rationality and non-rationality as overly categorical. The alternatives proposed for a more inclusive and plural citizenship involve the participation of marginalised groups in policy making (Lister, 2007a), so that the standpoints of people who are otherwise excluded become influential (Kabeer, 2005).

I found that support for communication, the basic requirement for participation, was fragile in the lives of people in this study. Margaret was able to exercise control by depressing a switch with her arm, but that equipment was rarely in use. Marilyn had reached her thirties before any serious attempt had been made to study her communication, through videoing, and to work out patterns in her responses. Nor was support for participation only a question of technology. Broken relationships (Phil and Marilyn), insufficient time, task-oriented care and an unwillingness to accept that what the person thought was valid (Anne) could all overshadow the person's chance of being heard.

There are particular challenges in enabling the participation of people who do not use speech or have pre-intentional communication, although as I referred to in Chapter Two there is an increasing body of work on these issues. It is not realistic to expect some people to express a 'view' on an abstract issue. However this does not mean that their participation is impossible because they may well be able to convey what is important to them and what their life is like. The condition that needs to be satisfied for them being able to do so is support. They can be enabled by others to contribute, but they will not be able to do it alone. Such support may consist in specific communication support, but it may also be a trusted person whose presence can increase their confidence, or even someone to speak on their behalf without specific direction from them, but out of a deep knowledge of their preferences and interest (sometimes called non-instructed advocacy). It should be possible to build the capacity of the policy community for more inclusive participatory strategies, given that many of the requirements are applicable to a wide range of needs. For example, in the policy interviews there were indications of some attempts to give people with learning disabilities greater influence over service developments, and there have

been further developments since. However, sustained attempts to involve people who require considerable communication support remain rare.

Participation is seen as a key process for enabling access to social rights. In this section I have argued that recognition of the need for support to participate is essential if some people are not to be disadvantaged from the opportunity of receiving respect for who they are. In the next section I turn to my final theme, the question of how best to ensure social justice and public responsibility for the inclusion of all.

3.4. Redistribution and recognition

The fourth theme is redistribution and recognition. This phrase is a shorthand for a debate about what is necessary to achieve social justice. Specifically it refers to the arguments articulated in the debate between Honneth and Fraser about whether material redistribution is sufficient (Honneth) or whether recognition of claims for identity through the struggles of marginalised groups can be combined with a distributive approach (Fraser) (Fraser and Honneth, 2003). It therefore addresses the question of what is needed in public policy terms for people to be able to access their rights to equal citizenship, a subject of particular interest in the face of major retractions on public spending. This theme also connects with concepts of citizenship. The concept of cultural citizenship references the different dimensions of identities, such as race and gender, and challenges the exclusionary impact of narrowly defined concepts of the normalised citizen (Stevenson, 2001). My fourth theme 'redistribution and recognition', therefore brings together a number of interconnected themes within the thesis including, the importance of cultural dimensions to exclusionary processes, 'high support needs' as a public responsibility and claim on public expenditure, how others can hear that claim and what the implications are for the best strategy for inclusive social justice. I have left this theme until last because it touches on the boundary of private need and public responsibilities, on intimacy and political exposure and therefore connects the

individual experiences of the case studies with my overall theme of inclusive citizenship.

I identified issues of distribution, of how to allocate material resources, as significant, both at the individual and the strategic level. The selection criterion for the case studies was the assessed need for at least one-to-one support on a 24-hour basis. However, where the person lived with their parents, support after 3pm was seen largely as a private, family responsibility. The only person with profound impairment who was receiving a different form of support had no family involvement in her care. Respite was available to these families, but support for the young person to go out in the evening was much more problematic and was provided, if at all, informally and through befriending or the use of Independent Living Fund monies. There was thus a mismatch between the use of funding and the needs and rights of the young person to go out, meet their peers and live as an adult.

All the case study participants had been assessed as requiring ‘additional’ support for some reason. In Chapter Five I analysed these reasons and concluded that needs for assistance with all forms of personal care and concerns about public risk were rated more highly as a case for support than mental health problems, especially if these primarily raised issues only for the individuals and their family; again the implications for the person’s inclusion seemed less of a concern (for example, Anne). In the policy survey, respondents identified provision of adequate resources as their top priority, and yet the interviews showed that the picture was more complicated than this, and that they were struggling to accommodate claims to provide services to people whose needs challenged their existing patterns of provision, people with autism, people with behaviour that challenged, people with mental health problems, the same types of needs that were represented in the case studies.

I would therefore argue that issues of recognition were bound up with the question of resources and their distribution. The needs of individuals in the study which were accepted as a responsibility for public funding, and then primarily only within working hours, were those of care and supervision. Rights to autonomy, self-development, relationship and community connectedness

were treated as more marginal in the resource allocation system. To create a different response to their needs would require a change of view of the purpose of care. It has been suggested that an 'emancipatory' view of care could be taken as an alternative to the view of care as either dependency or discipline (Hughes et al., 2005). The use of person-centred planning approaches is one way in which this theory can be translated into a practical approach that is applicable to the people in the case studies and to the development of services for people with learning disability more generally (Etherington et al., 2009).

Acceptance of the public responsibility to fund support to enable people to live a fully inclusive life, whatever their impairment, would also entail recognition of their rights to a life as an independent adult. This claim also involves issues of material distributional and cultural recognition, of universal rights and of specific claims. It is here that the assumptions of citizenship behind different social policies become relevant. Such claims are unlikely to be prioritised when economic productivity is the overriding characteristic of the 'good' citizen. Nor is the argument that society should provide support to those who cannot contribute out of a moral obligation, which was the principle that underlay the original postwar welfare state settlement, satisfactory, because it perpetuates a divide between producers and recipients. One response that has been offered to legitimate claims to higher social value by those seen as economically unproductive is to propose an 'ethic of care' as an alternative to the valuing of economic productivity (Williams, 2001, Williams, 2005). However, the elevation of 'care' as a justification for claims to the means for independent living may not only be unacceptable to the independent living movement, but also fails to address the problem of why people who do not see themselves as care-givers or care-receivers should be persuaded by this claim.

Taylor-Gooby (2009) distinguishes between redistribution on the basis of reciprocity (where the need is shared) and redistribution to meet the needs of other groups, which he describes as inclusion. The first he describes as horizontal distribution and the second as vertical distribution, affecting minorities whose needs are less understood. I have described (Chapters One and Two) how the cultural 'othering' of people with learning disabilities has been seen as a significant cause of their disadvantage and in my own study, how

experiences of marginality in public places (Chapter Six) and of a problematised place in service development, especially for those seen as difficult to 'integrate' (Chapter Seven) may contribute to exclusion. For these reasons it seems to me unsatisfactory to rest the claim to public support solely on the grounds of the responsibility of the majority to respond to the different needs of a marginalised group, as this will continue to reinforce 'otherness'. Taylor-Gooby (2009:12) identifies trust, together with reciprocity and inclusion, as the requirements for social citizenship. On the basis of this study I would argue that the development of such trust depends on two things: on people having the opportunity to experience, as I did in this research, what it is to know someone who may know and experience the world differently from them and secondly, that they come to view vulnerability, not as the characteristic of others, but as an identity they share. The first condition returns to the theme of relationship and inclusion, for unless people are included in wider networks and not confined to the private family space, there is no possibility of influencing wider social attitudes. It also recalls the analysis of Young (1990a), that social justice begins with a claim made on people by people (see below).

Turner has elaborated the case for the vulnerable body providing the basis for a new sense of social solidarity (Turner, 2006), and Shakespeare has echoed his argument that Disability is not a fixed identity, a 'them' and 'us' position, but rather a shared identity that could be the basis of a new social contract (Shakespeare, 2006). In a thesis which aims to theorise Disability in the context of citizenship and is entitled, 'Citizenship and Vulnerability', Beckett also arrives at the conclusion that a shared sense of vulnerable personhood could be the basis for moving from the politics of difference to alliances between groups with different identities and that could lead not only an empowering engagement with citizenship to achieve human rights, but also to agreement on the need for a strong welfare state (Beckett, 2006a). While I do not accept Beckett's conclusion that citizenship is best thought of as a process rather than a status, I think that my conclusions do sit within this family of ideas about how a new more inclusive social contract could be built. My contribution rests in suggesting why vulnerability must embrace the spectrum of cognitive and social competence, as well as physical differences, as part of a shared story of trustful citizenship.

3.5. Conclusion on key themes

In answer to my first research question therefore, my research showed that people experienced inclusion through relationship, although because they generally enjoyed a small number of close relationships, rather than a wider number of looser ties, their experiences were more likely to lead to belonging in private than in public spaces. Exclusion, by contrast, was often experienced as an absence, through the lack of access to support with health or communication needs, which directly reduced the opportunities for inclusion.

My other substantive research question concerned the impact of service development and thinking on the structuring of experiences of inclusive or exclusionary processes. The study showed that the ways in which services were funded could reinforce exclusion by constituting some needs as primarily a private responsibility, and not prioritising support that would enable people to participate. At the strategic level also, ambivalence as to the boundaries of health and social care responsibility could problematise some people's rights to inclusion, and 'high support need', whether interpreted as excess cost or unmanageable need, could be a rationale for exclusion. However, some commissioners had values that led them to presume that it was their job to try to find solutions in order to sustain people in the community, showing that attitudes and a willingness to lead could make a difference to the solutions chosen.

In the next section I discuss the contribution of my study to the development of research for people with high support needs, beginning with a critical appraisal of my own work.

4. Study limitations and implications for research practice

The sampling strategy for this study was designed to reflect the different reasons for which people might be assessed as requiring a high level of support. The disadvantage of selecting a support measure as a criterion for entry to the study is that a limited and sometimes arbitrary set of reasons were used to allocate additional support and the people in receipt of it will not have reflected the characteristics of all those who may have had comparable levels of need. Moreover, the small number of case studies I conducted (14) makes it difficult to distinguish general issues from the effects of individual personalities and situations. I am aware of two gaps in particular that resulted from the composition of the final sample; the absence of any black and minority ethnic participants and the omission of people that had already been discharged from long-stay hospital into supported living arrangements. The inclusion of people in the latter category would have enabled me to find out more about the position of people some time after discharge. Meanwhile, the prevalence of severe impairments is known to be higher amongst Black Asians - by some three times amongst ages three to 34 according to Emerson and colleagues (1997) - while work based on the Leicester Register (McGrother et al. 2002) which compared the experiences of South Asian and white adults found lower access to services amongst Asians. Therefore my study cannot claim to describe circumstances that are representative of all those with high levels of need or perhaps more common amongst excluded minority ethnic families who are likely to be particularly marginalised.

In addition to limitations arising from the way the study sample was drawn, a limitation of the design must also be acknowledged. The premise of the study was that people with high support needs would reveal incapacities in the service system. I did not therefore address the exclusions experienced by people who are below the threshold of receiving support from services, for example people with mild impairments and particularly people on the autistic spectrum who may fall between the remit of learning disability and mental health services. The experience of local area co-ordinators in Scotland suggests that there are many

unmet needs for support for inclusion among these groups, both amongst people living with families and those supported by services (Stalker et al., 2008).

In the conduct of the study itself there were considerable limitations in the extent to which I was able to fulfil my aspirations to extend inclusive research to people with high support needs. I began the work with no experience of research with people with severe communication impairments. Had I been better informed of the practice of assisted communication and issues of validity of interpretation (for example, Grove et al., 1999), I could have sought support to develop more structured approaches through which I could have applied some criteria to assess the ways in which I was interpreting the responses of people with profound impairment. The time I spent with most participants was short and I did not avoid reproducing the exclusions that some commonly experienced, for example when I did not succeed in finding a way for either Colin or Ruth to contribute to the research. This remains an exploratory study and in future I would wish, conditions of access permitting, after having scoped out the possibilities for engagement with the participants as in this study, to continue in a more focused way with each one to explore their experiences.

Compared with more recent developments (Bunning et al., 2009), this study did not use a sufficiently wide range of media and approaches to increase the participation of the people in the study and thereby increase their capacity to contribute. A reasonable criticism of this work would be that I did not sufficiently adapt my practice and that the relative unstructured encounters, based on the typical qualitative research interview, may have created communication barriers for some participants, as noted in Chapter Four. Despite acknowledging that text was not accessible to almost any participant in the study, I did what I knew best, which was to translate the research sessions back into written media. I found that the tape recorder provided a low tech way to engage participants and used it to give them back a record of their stories, but there are many ways in which, given resources, I could have engaged them more and applied my thinking about interactive approaches in concrete ways to increase their participation. For example, I might have worked with some participants to record experiences of their daily lives. Manning has successfully used digital storytelling techniques (2009) and has found that the use of digital

media can be used to check back interpretations, and enable people to shape and own their own story. A serious limitation of my research is that there are no alternative versions with which to compare the accounts I have provided of the participants' experiences.

Finally, the study was not directly informed by the participation of self-advocacy groups, a position which I no longer find defensible. At the time I thought that there would not be groups who represented the interests of people in this study, but my subsequent experience has shown me otherwise. I shall be working with a group of self-advocates to prepare a summary of the study for web-based dissemination. By the standards of emancipatory research, a key question is whether the outcomes of the study will contribute to debates about future policy and practice. This research has taken too long to be written up as a thesis and in that sense I have devalued some of the experiences I researched. On the other hand local authorities and their health service partners in Scotland, as in the rest of the UK, are currently grappling with the issues of high cost packages, with the equity issues in allocating resources fairly, and with continuing use of inappropriate service models such as out-of-area placements. As part of a national group that is looking at these issues, I have used my experience in this study to contribute to the principles that should guide service development.

I set out to answer the question whether a 'mainstream' qualitative researcher could engage effectively with people who might often be excluded from research participation. My experience was that each study participant made a contribution to answering the research questions, despite my different levels of engagement with them. The capacity of the person to respond to verbal questions or to understand the nature of research was not necessarily a limitation on the significance of their contribution. In fact, it was from the study participants largely that I learned how to approach the research and I came to conceive of myself as the incompetent researcher who needed to increase her capacity, and that it was the study subjects who were the experts.

My research suggested some of the conditions that might increase the capacity of researchers and the opportunities for people with high support needs to take part in research. Fully inclusive research would allow for differences in the levels and nature of control that different participants may be able to exercise throughout the research process. Those not able to engage directly, for example, in the design of research instruments, might be able to influence them indirectly by showing what does and does not work. I identified an attentive stance on the part of the researcher as an important strategy for enabling research participation. Despite any technical limitations, the ethical and methodological issues that I identified were different in degree, rather than in kind, from those of any research situation (Denzin, 2001).

My emphasis on the relationship between the researcher and participant has risks as well as benefits. Reflection on the ethical issues involved in co-research is increasing awareness of the standards required (Ward, 2004, Walmsley, 2005, Johnson, 2009). The issue of safeguards is an important one and is not resolved by merely restricting access to research. Given the importance of the relationship between the person and the researcher, a choice of researcher from within a research team might be desirable in order to provide research participants with opportunities to reveal more and different facets of themselves and of their lives. Other issues that my research highlighted included: time to gain access and obtain contextual information about the person's life; time to build a relationship with the person; the opportunity to be flexible in the number, timing and length of meetings; and, the freedom to pursue a wide range of approaches and media within the same study in order to be able to engage with the person and their communication in the way that best enables them to contribute. The emancipatory research paradigm, based as it is in the social model of disability, remains a key reference point because the principles it emphasises, that the research should be in the interests of the person and that they should be in control as much as possible, need to be at the core of research with people with high support needs also.

The prospects for researchers being able to enter this field effectively have increased considerably since I conducted this work. For example, Communication Forum Scotland has produced a Talk for Scotland Toolkit

([http://www. communicationforumscotland.org.uk](http://www.communicationforumscotland.org.uk)) to improve capacity to engage with people who do not use particular communication systems. I have argued that it is the responsibility of the research community to increase its communicative competence, and I hope that my research can contribute to such issues being addressed in future social research on citizenship and participation.

5. Implications for commissioning and for future policy directions

An area of current concern to which this study offers a contribution is that of eligibility for adult care services. On the basis of my argument above, a dependency-based measure of need as a basis for allocating scarce resources may not even benefit those with the most severe impairments, who also require support to develop their autonomy and increase their opportunities. A change of language to a support-based measure of need may still essentially be a measure of a form of adaptive behaviour (Brown et al., 2009). An approach more likely to result in services being oriented to the outcomes that will lead to longer term benefit to people with high support needs is one that addresses the potential of public resources to contribute to, or prevent threats to, their dignity, autonomy and inclusion, such as was proposed by the Commission for Social Care Inspection (2008). Such an approach might also enable commissioners to justify investment in advocacy, communication support and staff training, as well as direct care services. Without changes in staff attitudes and competence, newer models of service, such as day opportunities, cannot deliver expected outcomes.

Since this study was conducted, two developments that have foundations in the disabled people's movement have emerged to greater prominence in the policy landscape in Scotland, as elsewhere. These are self-directed support and Independent Living. Both offer the prospect that disabled people can achieve greater control over their lives and envisage changes to the relationship between the disabled person and the state. However they are being taken up by the Scottish Government at a time when its main strategic objective is economic

productivity and the reduction of inequalities primarily through economic development; social solidarity is to be built through greater economic participation (Scottish Government, 2007, Scott and Mooney, 2009). Therefore there must be doubts as to how far, as policies, self-directed support and Independent Living will achieve empowerment for disabled people, rather than becoming diverted as a means of regulating or limiting social care spending.

Self-directed support is a term for a range of mechanisms, including Direct Payments and individual budgets, by which individuals who have been assessed as requiring a support service can take more direct control over that service, either by receiving the money and effectively commissioning the service themselves, employing personal assistants, or having the budget for their service individualised and spent in ways, and to achieve outcomes, that they themselves largely determine. Salient features of self-directed support include user control over the money for the service, self assessment and a focus on achieving outcomes. With an individual budget people may choose to spend the money in different ways to improve their lives, for example music lessons or gym membership. Direct payments developed from the demands of the Independent Living Movement for disabled people to have control over their own support, and individual budgets derive from the In Control model developed by Simon Duffy (2006), the first stages of which were starting in North Lanarkshire at the time the fieldwork for this study was drawing to a close (see Chapter Five). A report on seven people who had received an individual budget for three to nine months in North Lanarkshire has reported positive outcomes, as did evaluation of 196 people with experiences of individual budgets in 17 English local authorities (Etherington et al., 2009, Hatton et al., 2008). However as yet, the numbers of people with access to self-directed support in Scotland are small. In 2008 2,605 people in Scotland were reported as receiving Direct Payments, of whom only 704 were people with learning disabilities (National Statistics, 2008).

Self-directed support is associated with 'personalisation' in which services are made responsive to individualised user choice. As such it has been criticised as being part of a consumerist movement and of transferring risk to the individual and away from collective welfare provision (Ferguson, 2007). However self-

directed support was conceived as a means to achieve Independent Living. As defined by the disabled people's movement, Independent Living covers more than care services. It is built on the presumption that human beings, regardless of their impairment 'are of equal worth and have the right to participate in all areas of mainstream community life' and that they should be 'empowered to make choice and exercise control in their everyday lives' (Barnes and Mercer, 2006:184). By 'Independent Living', the Independent Living Movement does not mean that people should be able to do everything for themselves, but rather that they have a right to the support that enables them to have independence. Independent Living has been embraced by the Commission for Equality and Human Rights in Scotland through the creation of an Independent Living Project, advised by a Steering Group of disabled people, and sponsored by the Equalities Unit in the Scottish Government as a cross-Government initiative. The project is striving to be inclusive of people with learning disabilities and includes representation from People First Scotland.

Pearson has explored the impact of competing discourses of social justice and the market in the implementation of direct payments (Pearson, 2000, Pearson, 2006). She found that the discourse of user control was liable to be overwhelmed by the necessities of a cash strapped social care market and, in her Scottish example, that the control that users could achieve through a cash payment was limited by the restructuring of welfare that led to inequities in the availability of a provider market. In my research I also found differences in the infrastructure of services between local authorities which would limit choice. The advent of Single Outcome Agreements with the devolution to local government level of control over how national outcomes are to be achieved, and therefore resources distributed, is likely to perpetuate this pattern.

I see both parts of my research as relevant to these issues. The case studies indicated (see Chapter Five) that inflexibility of resources, including centralised control over their use and restricted options for how money could be spent, resulted in inability to meet needs. In two examples (Tracey and Michael) local social workers and managers were frustrated at their lack of authority either to spend above a ceiling or to use resources flexibly to meet needs. In the survey of

commissioners I found that inherited patterns of investment in services, in particular in buildings-based day services, were a major limitation on being able to develop a different pattern of provision that might offer more opportunities for inclusion. Therefore, a system of resource allocation which would bring together different sources of funding to create more individualised packages of support, as premised in individual budgets, seems to address some of the major barriers that I identified towards people receiving the flexible support that they required. Another key theme of this study has been the importance of access to support to enable people to realise inclusion in the ways that mattered most for them, for example to be able to have the security of continuing support from people that were important to them, as exemplified by Marilyn, Sheila, Ailsa and Stuart, or from people who communicated with the person in their preferred way, as was powerfully illustrated by Phil.

However, there must be concerns that self-directed support will only be as empowering as the intention with which it is implemented. In my survey, there were some commissioners who were committed to try and lead change to ensure that people with challenging needs got the support they needed to be included. However, others operated on the principle that services could only meet certain types or levels of need. With the prospect of restricted spending on public services for the foreseeable future, there are risks that access to self-directed support will continue to be limited and vary across the country, or that implementation of the policy may be distorted by the over-riding need to reduce expenditure. There is a contradiction between an agenda of user involvement and choice on the one hand, and a reduction in the number of service providers as a result of service re-tendering to reduce costs on the other. The new prominence of Independent Living, partly as a strand of the Scottish Government response to the Ministerial Duty on Disability Equality, may provide some security within Government, for an agenda that is closer to the goals of the disabled people's movement. However it remains to be seen how much leverage it will have across the rest of government, quite aside from the impact of decentralising spending to local authorities through Single Outcome Agreements.

My research therefore, though conducted at the very beginning of the development of Individual Budgets, has a direct contribution to make to current debates about the future of social care. Its implication is that people with severe impairments and additional needs will continue to be left behind unless there is specific recognition of their needs for support, without which they will be unable to take advantage of opportunities. Newer models of allocating resources and offering greater control will also fail to impact on their lives unless these are accompanied by processes and investment that enable them to have access to the time and personalised attention they need to establish their wishes, and to have a support plan that meets their individual needs.

6. Conclusion

My first conclusion concerns the status of people with learning disabilities as citizens. Rather than expect citizenship rights to lead to equality, I conclude that people can be equal citizens only if they can access the means to participate.

My second conclusion concerns fairness. I find that the overall implication of this study is that people need different opportunities to achieve equal outcomes. Differences in resource allocation may therefore be fair if they result in overcoming systematic disadvantages.

My third and final conclusion concerns recognition. Normalisation approached the problem of exclusion by attempting to revalue people with disabilities according to accepted standards of social value. It therefore failed to provide a basis for developing different notions of social value, or for solidarity across the boundaries of different identities and interests. I conclude that for people to enjoy the 'valued experiences' that John O'Brien and others have desired on their behalf, there is a need for society to accord a higher social value to social participation. Without recognition of the needs for support for participation as

a public claim and a public responsibility, rights cannot be accessed and people will receive differential responses to needs.

My conclusions about inclusion apply equally to the practice of research. Broadening research participation, like citizenship itself, demands practices that provide support for understanding information and accessing support to communicate views and meanings. There are strong parallels between the issues for research and Lister's account (2007a) of the need to create inclusive spaces to enable people whose voices have been marginalised, such as children and people in Poverty, to contribute to policy making and for the competence of policy makers to be built up so that they can become better at including people on their own terms. The claim for them to be heard needs to be made on the grounds of equality, for otherwise policies and services are being devised without knowledge of their impact on people for whom the outcomes cannot be assumed to follow in the same way. To leave them out is to deny respect.

I have argued that rights alone are not enough to ensure social justice for people with learning disabilities who encounter structures, norms, rules and practices that may restrict their access to such rights. The marginalisation of people with learning disabilities is likely only to be reinforced by inclusion strategies that depend solely on the assertion of citizenship rights, or on social care reforms that rely on the exercise of rational choice or on economic participation to help shape the system to achieve better life outcomes. Social justice for people with learning disabilities will require a combination of strategies including rights, procedural fairness, and support, including material support, to maximise the capacity to participate.

The barriers to inclusion experienced by people with learning disabilities hold lessons for inclusive citizenship more generally, insofar as the inclusion of people with learning disabilities challenges the idea of the autonomous citizen capable of independent decision-making and rational choice. A fully inclusive basis for inclusion, therefore, entails accepting shared identities as supported, incompetent subjects.

LIST OF APPENDICES

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Appendix 1: Pen Pictures

Jennifer (1) lives at home with her parents and goes to a day centre some distance away. She previously attended a blind centre and her mother reports that she had a struggle to show that she has vision. Jennifer's keyworker also feels that so far services have not provided a careful and individualised response to maximise her inclusion. I interview her mother at home and spend time at the day centre and also on an outing to the park. Jennifer is in a wheelchair and needs support with all aspects of daily living. She vocalises and uses facial expressions but does not speak. She loves to go out, but her only regular evening outing is to a voluntary-run disabled club. The workers at her day centre acknowledge the restrictions on providing evening support.

Margaret (2) is a young woman who lives at home with her mother. She attends the special needs unit of a day centre five days a week, but is being considered for an individualised college placement. The rest of the time her mother provides her care, with access to some rolling respite. Margaret's health needs often interrupt her attendance at the day centre, but through her family she has connections in the local community. I first meet Margaret through her mother's words, then through pictures and finally in person. I spend time with her at the day centre, and on a visit to the sport's centre, and I interview her key worker. Margaret is aware of a great deal that is going on around her, although she does not speak. I observe the importance of key relationships to Margaret's identity and wellbeing. Her family, and her mother in particular, are at the core of her life.

Anne (3) is in her early thirties and lives at home with her parents and a sibling. She attends a nearby day centre five days a week where she often receives one-to-one support. Anne has a mental health problem and is sent home from the day centre when she is violent to others. She is included in her family and their networks but they do not feel that she can safely go out by herself. Her parents struggle to manage her at home and suspect that she may be ready to move on from the family home.

Marilyn (4) is in a supported living environment in a residential area of the city. There are three other residents in the house but each person receives individual support. Marilyn used to live in a larger hostel and her support is tailored to enabling her to have more choice and independence, and to limit self-harming behaviours. Her bedroom is her own space and she takes me upstairs to see it and we sit on floor together. Marilyn is very interested in other people but does not communicate verbally. She has recently been diagnosed with Rett syndrome. She now attends a day centre for part of the week and goes out and about socially with the support of two workers. When I visit Marilyn at the day centre she is not taking part in the activity around her and the day centre workers says she has no special friends there. I also go out with her and a support worker for the evening and Marilyn enjoys herself watching others in the pub. A similar outing is independently videoed.

Ruth (5) is supported in a group home by a provider agency and attends a day centre four days a week and a specialist day facility run by another voluntary agency on the other day. She is in late middle age and is visually impaired. She is not from the local area and talks in a continuous 'stream of consciousness' manner, which seems to allude to past incidents, especially in childhood. I visit her at home and, although made welcome, have limited success in interviewing her.

Rob (6) was brought up in a children's home and has also lived in a large hostel. He is considered to be at risk of (sexual) offending behaviour. He is now supported by an independent provider in his own tenancy, with one-to-one and sometimes two-to-one 24 hour support. He attends a day centre for part of the week. He is also receiving therapy from a psychologist. His support workers think that the only likely alternative to his current support arrangements is a secure hospital. Rob can now go out into the community with supervision, for example shopping or to the pub for a drink. However his support workers keep very close to him physically and constantly warn him about his behaviour, and as a result Rob's freedom is very limited. At home the environment is more relaxed, although Rob can be violent towards his support workers. Rob takes pleasure in his own home and possessions. There he can have freedoms, for example telephoning his family and answering the front door.

Tracey (7), a young woman, lives at home with her mother. She now attends a specially funded day-care service which is specifically designed for people whom other services have not been able to support. However after she left special school it was several years before this arrangement was put in place. Eventually she was admitted to a registered health care facility after she had been excluded from a day centre and her mother was finding it impossible to manage at home. She was diagnosed with a severe and enduring mental health problem for which she now receives medication and support from a CPN. Tracey is still considered to be 'vulnerable' and is not expected to be able to travel independently for many years to come. I meet and interview Tracey at the day service and participate in some activities with her as well as travelling to her home with her and the support worker. I also interview her mother.

Michael (8) is in his late twenties and lives at home with his parents, spending four days at a day centre with additional support. He has profound and multiple impairments and complex health needs including a rare genetic condition. Safety concerns arising from his severe epilepsy account for his two-to-one support at the day centre. His family has fought for services, especially when Michael was leaving school, despite his profound impairments having been present since birth. Engagement with him is fleeting as he is often asleep. I find out about Michael's situation by talking to his mother at home and spending time with him and his long term-support worker at the day centre, who also talks to me at length. Michael and his support worker are videoed together.

Mairi (11) lives at home with a sibling. She no longer attends a day centre full-time. She still goes on two days but she is now also receiving one-to-one support to take part in activities in the community. She has a part-time job and goes to keep-fit regularly. By the account of Mairi herself and those who know her she has changed a great deal since she has been able to try lots of new activities. The support workers report that when her mother was alive Mairi was allowed little choice in what she did, how she dressed or where she went. Mairi herself tells me that the greatest sadness in her life was the death of her mother. In 'the community' Mairi is very still very visibly a 'client'. She has been assessed as needing support presence at all times because of her epilepsy. While we have

lunch on a café the support worker sits at a nearby table using her mobile telephone.

Sheila (12) is a long-term hospital resident. At present the hospital is both her home and her community and she takes me on a tour of it. She lives there (in a three person unit), works there and visits her friends there for cups of tea. She is aware that the hospital is closing around her. She has had five 'placements' in the community, all of which have broken down. She says that she is frightened of being on her own without anyone to talk to her and it makes her 'nerves' bad. According to the nurse who has known her for over thirty years, Sheila's behaviour deteriorated in her new home and the support providers were ultimately unable to manage her extremely challenging behaviour.

Stuart (13) has been in institutions since he was a child. He is detained under Section 55 for past offending behaviour. One implication of this is that he has to be supervised by a member of nursing staff with a certain level of training whenever he goes out. In the hospital he works regularly at his art, something which he and the psychiatrist regard as essential for his wellbeing and stability. A community placement has been identified for him. However it is not clear that there will be funds to provide a sufficient level of supervision to enable him to go out to access equivalent opportunities in the community. A self advocate, he takes an interest in my tapes, hoping to record his experiences for the benefit of others.

Phil (15) still lives on the locked ward of a long-stay hospital. He is hearing impaired and we meet to explore his expectations of living in the community with a worker who can sign. I am warned that Mike lives entirely in the present and that his autism makes it unlikely that he will reveal emotions. However during the course of the session he reaches for the study information sheet and uses the blank spaces on it to write down people's names. He writes down the name of the place where he comes from and the names of his immediate family, including his father who has died, and the workers he has known who have been able to communicate with him through sign language.

Colin (16) lives in a supported living arrangement with three other people who also challenge services. The house is receiving some back-up from a health team because the provider agency is struggling to manage the needs of residents. The neighbours next door are trying to move. Colin has been discharged from hospital and has a job. He says he loves his room and enjoys swimming. He has a part-time job but his support workers feel that he is not safe out by himself as he runs across roads. Colin spends a large part of our two sessions listening to tapes and I find it find it very hard to build a rapport with him. As I leave he points a (toy) gun at me.

Ailsa (17) is in her middle years and is detained under the Mental Health Act. She is currently living in a specialist health facility. Numerous previous attempts to support her in the community have failed and she herself is vulnerable, with a history of having been abused. I visit her in the evenings while she tells me her story and her hopes and I tape-record our sessions. She has been building up a relationship with the family of a worker who may offer her support in future. She is waiting eagerly for a house to be found for her.

Appendix 2: Data Items

Reference No. Case study/ Session	Format	Date	Times	Who	What	Where
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1. Jennifer

1/1	F/Notes	10/05/99	09.30 - 11.55	Key worker Jennifer Others at day centre	Interview Observations Observations	Day centre
1/2	F/Notes	01/06/99	12.15- 15.15	Day centre workers Jennifer Others at day centre	Observation of trip out	Day centre Bus Park Bus
1/3	F/Notes	05/06/99	14.30- 15.25	Mother	Information Consent Interview	Home

2. Margaret

2/1	F/Notes	07/05/99	14.00 - 16.00	Mother Sister Margaret (brief)	Information Consent Interview Conversation Observations	Home
2/2	F/Notes	25/05/99	09.15 - ?	Key Worker	Interview	Day Centre
2/3	F/Notes Photo	23/06/99	13.20 - 15.15	Day centre workers Margaret Sports centre worker	Observations	Day centre Bus Sports Centre Bus

3. Anne

3/1	F/Notes	29/7/99	10.00 - 11.30	Anne Support worker	Information consent	Day centre
3/2	F/Notes	Summer 1999	Brief	Mother	Conversation	Telephone
3/3	F/Notes	17/8/99	14.00-15.30	Mother Father Brother	Interview	Home
3/4	F/Notes	27/08/99	10.00 - 11.00	Anne	Interview	Day centre
3/5	F/Notes	15/10/99		Mother Key Worker	Conversations	Telephone
3/6	F/Notes	17-10/99-24/01/99		Anne Parents	Weekly diary kept by parents	Document
3/7	F/Notes	6/03/00	11.30	Parents	Interview	Home
3/8	F/Notes	21/03/00	11.00	Mother	Conversation	Telephone

4. Marilyn

4/1	F/Notes	10/09/99	11.45-13.00	Marilyn Support workers Other resident	Information Consent Observations	Home
4/2	F/Notes	14/09/99	19.00-20.35	Support Worker Marilyn Public	Visit out	Car Pub Car
4/3	Transcript and F/Notes	16/09/99	10.00-11.00	Team leader (support provider)	Interview	Home
4/4	F/Notes	06/09/99-19/09/99		Marilyn Team leader	Weekly diary	Document
4/5	Transcript	25/10/99	10.30-12.00	Day centre worker Marilyn	Interview Observations	Day centre

5. Ruth

5/1	F/notes	21/10/99	? - 12.15	Acting manager (support provider)	Information Consent	Home
	Not able to transcribe	?/10/99	16.15-17.30	Ruth	Interview	Home
5/2	Transcript and F/notes	17/12/99	16.15 - 18.00	Ruth	Interview	Home

6. Rob

6/1	Transcript	22/9/99	09.30-11.00	Support workers 1 & 2 Rob	Information Interview Observation Access	Day centre
6/2	F/notes	30/09/99	19.00-20.00	Support worker 1 Rob Public	Interview - out Observations	Pub
6/3	Transcript F/notes	06/10/99	20.00-21.00	Support worker 2 Rob	Interview Observations	Home

7. Tracey

7/1	F/notes	25/07/98	09.30-09.50	Tracey Social work area manager	Interview	My office
7/2	F/notes	02/09/99	13.30	Tracey Social work area manager	Conversation	Telephone
7/3	Transcript	26/10/99	?	Tracey Social worker	Interview	Social work department
7/4	F/notes	27/10/99	11.00-12.30	Tracey Mother	Consent Interview	Home
7/5	F/notes	7/11/99	11.00-12.15	Key worker	Interview	Day centre
7/6	F/notes	14/11/99	13.00-15.00	Tracey Support worker	Interview Observations Daily activity	Day centre
7/7	F/notes	?/11/99	10.30-17.30	Tracey Support worker Mother	Spend day Interview Observations	Day centre Bowling Home
7/8	F/notes	27/11/99	11.15-12.30	Tracey Support worker	Observations	Day centre
7/9	F/notes	07/12/99	13.00-16.00	Tracey Support worker	Files	Day centre
7/10	Transcript	07/12/99		Tracey Day centre manager Tracey	Interview Singing	Day centre Office
7/12	F/notes	07/12/00		Case note writers	Case records	Day centre

8. Michael

8/1	F/notes	26/10/99	30 mins	Mother (Michael present)	Information Consent	Home
8/2	Transcript F/notes	?/10/99	2 hours	Support worker Volunteer (Michael present)	Interview Observations	Day centre
8/3	Transcript	?/10/99	2 hours	Support worker Volunteer (Michael present)	Interview Observations	Day centre
8/4	Transcript	?/10/99	14.00- 16.00	Mother	Interview	Home
8/5	F/notes	14/02/00	11.58- 13.30	Support worker Volunteer Michael	Lunch Observations	Day centre
8/6	Transcript and F/notes	14/03/00	Half a day	Day centre manager Case files	Interview Care package history	Day centre Office
8/7	F/notes	25/10/00	16.30- 17.45	Area team social worker	Interview	Social work office
8/8	F/notes	02/11/00	09.45	Mother	Conversation	Telephone call

11. Mairi

11/1	F/notes	?/09/01	12.10- 15.00	Project Manager Support worker Mairi	Information Consent Meeting	Cafes Car
11/2	Transcript and F/notes	Few days later	11.300- 13.30	Mairi (Support worker present)	Interview	Cafe
11/3	F/notes	13/09/01	12.45- 14.30	Mairi (Support worker present)	Interview	Cafe
11/4	F/notes	20/09/01	12.10- 14.05	Mairi (Support worker present)	Interview/ Feedback - Mairi's story A&E encounter a few days later	cafe

12. Sheila

12/1	Transcript and F/notes	18/10/01	2 hours	Ward sister Sheila	Information Interview	Hospital
12/2	Transcript and F/notes	01/11/01	09.00-10.00	Sheila	Interview	Hospital
12/3	Transcript and F/notes	15/11/01	08.50-09.48	Sheila Support Worker Hopital Manager	Community walk	Hospital
12/4	F/notes	13/12/01	08.55-?	Sheila	Closing session	Hospital

13. Stuart

13/1	Transcript and F/notes	21/10/01	?- 14.55	Ward sister Stuart	Information Consent Interview	Hospital
13/2	Transcript and F/notes	02/11/01	16.00-17.10	Stuart	Interview	Hospital
13/3	Transcript	23/11/01	1 Hour	Stuart	Interview	Hospital

15. Phil

15/1	F/notes	22/10/01	15.00-16.00	Phil Signer	Information Consent Interview	Hospital
15/2	F/notes	29/10/01	11.00-12.15	Phil Signer	Interview	Hospital
15/3	F/notes	11/11/01	10.50-12.10	Phil Signer	Interview	Hospital

16. Colin

16/1	Transcript and F/notes	13/10/01	1.5 hours	Colin Support worker	Information Consent Interview	Home
16/2	Transcript and F/notes	07/11/01	16.35-18.00	Colin Support workers	Interview	Home

17. Ailsa

17/1	Transcript and F/notes	29/10/01	13.00-14.30	Ailsa Nurse	Information Consent Interview	Secure health facility
17/2	Transcript and F/notes	06/11/01	2 hours	Ailsa	Interview	Secure health facility
17/3	Transcript and F/notes	13/11/01	19.00-20.00	Ailsa Support worker	Interview	Secure health facility

Appendix 3: List of Other Interviews

Ref.No.	Format	Date	Time	Who
MD/1	F/notes	13/04/99	14.00-15.00	Manager Day centre 1
MD/2	F/notes	26/04/99	09.30-11.00	Manager Day centre 2
MD/3	F/notes	26/04/00	11.30-12.30	Manager Day centre 3
CT/1	F/notes	21/07/99	14.30-16.00	Co-ordinator, Commissioning Team
DT/1	Transcript F/notes	25/10/00	Half day	Learning Disability Co- ordinator Services Development Manager

Appendix 4: Weekly Diaries

Anne's week

<u>MONDAY</u>	
8am	Wakened just before 8 o'clock. Had breakfast and medication. Had hair washed and blow dried. Dressed ready to go the Centre.
9am	Bus arrived to take her to Centre.
9.30am	Cup of coffee and a plain biscuit for her breakfast when she came into the Centre.
10am	Helped out in the training kitchen making sultana scone and she helped out with cleaning the kitchen afterwards.
12pm	Had a salad and yoghurt for lunch. She ate every bite then she had a Coke.
1.30pm	Had a good afternoon with in the flower arranging class making Xmas decorations.
3pm	Left Centre in bus and was dropped off at Aunt's house where she played with the dogs and watched TV.
5.30pm	Dad picked her up and she came home and had dinner.
6.30pm	Went with mum and dad to (nearby town) in dad's car. Dad was bowling. Had colouring books with her and chatted to her friends with mum.
10.15pm	Arrived home and got ready for bed.
<u>TUESDAY</u>	
7.45am	Wakened and had breakfast and medication. Chatted for a while and then got washed and dressed ready to go to Centre.
8.50am	Bus arrived to take her to Centre
9.30am	Had a cup of coffee and a plain biscuit when she came into the Centre
10am	Played table tennis and a game of pool in the games room with Sal.

Marilyn's week

<u>MONDAY</u>	
-	A.T.C. during the day (back at 3.30 pm).
-	relaxing in the house until dinner (quite self contained).
-	after dinner sat in her room with sensory lights and music for a while.
-	listened to staff playing guitar before bed (10 pm approx).
<u>TUESDAY</u>	
-	A.T.C. during the day (back at 3.30 pm).

12pm	Also had another coffee with her friend Mary. Went for lunch in dining room and had a salad and a yoghurt and a glass of orange juice. Took her medication	
2.30pm	After lunch was feeling unwell and complaining of a sore tummy. Went into relaxation room. Fell asleep for 1 hour. She washed her hands and face and was feeling much better	
3pm	Left Centre in bus and was dropped off at her aunt's who cares for her until 6 o'clock. Debbie enjoyed playing with the two dogs but did not want to go out for a walk.	- didn't do much before dinner (sitting around, etc.).
6pm	Came home in dad's car and had dinner then relaxed for a while reading magazines.	
7pm	She helped with dishes and clearing up after dinner.	- run in the car to (nearby village) after dinner with befriender.
7.30pm	Mum and she had a girlie night tweezing eyebrows and painting her finger nails and toe nails. She did some knitting and watched cartoons.	
9.30pm	Changed into her nightie and listened to music in her room.	- supper of ice cream before bed (10 pm approx)
<u>WEDNESDAY</u>		<u>WEDNESDAY</u>
7.45am	Wakened, had breakfast and medication. Had hair washed and blow dried then dressed ready to go to the Centre.	
9am	Bus arrived to take her to the Centre	
9.30am	Arrived at Centre about 9.30am. Had coffee and plain biscuit.	- A.T.C. during the day (back at 3.30 pm)
10am	Spent the morning watching video of Tom Hanks & Meg Ryan in You've Got Mail.	
12pm	Went through to dining room for lunch. Had a roast beef sandwich, a peach yoghurt & a glass of diet orange juice.	
1pm	Went to Café for a coffee.	
1.30pm	Due to staff shortage, she was unable to attend bowling. Instead a discussion group took place and she told everyone there	

<p>about her trip abroad.</p> <p>3pm Bus arrived to take her home. Dropped at aunt's house where her cousin was there. She enjoyed playing with the baby and the dogs.</p> <p>6pm Dad picked her up in the car. She came home and set the table then had dinner. She spent quite a long time with her knitting and looking at a catalogue.</p> <p>9.30pm Seemed to be tired and got ready for bed. She went up to her room to watch TV. Debbie did not sleep until about 11 o'clock.</p>	<ul style="list-style-type: none"> - spending time in house with staff before dinner. - watched dinner being prepared - laughing a lot. - during evening spent time in bedroom with staff looking at lifestory book. - staff offered Marilyn a riding hat to try on - not keen! - watched staff and other residents playing football in the lounge – fun. - distressed after evening bath (no obvious reason).
<p><u>THURSDAY</u></p> <p>7.45am Awakened, had breakfast and medication. Dressed ready to go to the Centre – talking constantly</p> <p>9am Bus arrived to take her to Centre</p> <p>10.15am We received a phone call from Centre to say she had struck out at another client. We picked her up and brought her home.</p> <p>11am Anne, her dad, mum and brother went in the car to (nearby town) to the Ten Pin Bowling Alley. She chatted to her friends and staff who are also her friends</p> <p>1.30pm Came home and had lunch after dropping brother at work. She had a little doze.</p> <p>3pm She was driven by her Dad to her aunt & uncle's house. She watched TV and played with the cats.</p> <p>6pm Dad picked her up and she came home and had dinner then helped to tidy up. Helping to dry dishes. She is very hyper and has talked all day and given everybody all her imaginary worries over and over again. She has watched TV and done some knitting.</p> <p>9.30pm Got organised for bed and spent some time in her room playing music before going to sleep.</p>	<p><u>THURSDAY</u></p> <ul style="list-style-type: none"> - long lie until 10 am. - speech therapist came for a visit - made a home video of 'intensive interaction' - seemed to enjoy the interaction. - went shopping at 'Au Naturelle' to look for things for her bedroom - became tearful afterwards - 3.30 pm (for an hour) - music therapy at East Park Home (private session), seemed to enjoy it. - relaxing evening at home - sensory lights, etc., in bedroom during evening.

<p><u>FRIDAY</u></p> <p>7.45am Awakened. Had breakfast and medication. Went back to bed for a lie in.</p> <p>9.30am Got washed and dressed. Played some music and watched cartoons on TV. Did some knitting.</p> <p>12.30pm Had lunch with mum and dad followed by a snooze. Dad took her for a walk.</p> <p>3pm Went to aunt & uncle's house. Other family there. She and Aunt took the baby to visit the swans and ducks at the local park. Then went back to the house to play with the cats.</p> <p>6pm Dad picked her up, drove her home. She set the table and then we had dinner. We relaxed and watched TV after she had helped to clear up after dinner.</p> <p>9.30pm She got organised for bed. Did some knitting while listening to music in her room.</p>	<p><u>FRIDAY</u></p> <ul style="list-style-type: none"> - up at 9 am - relaxing bath - baking cakes with staff for fund-raising day - Lisa Curtice came for a visit - drive thru McDonalds for lunch - during afternoon went for a leisurely run in the car - a relaxing rather uneventful evening in the house - sensory lights, etc., on in bedroom before bed
<p><u>SATURDAY</u></p> <p>7.45am She was wakened to have her breakfast and medication.</p> <p>10am She & mum spent some time on beauty regime, having a shower and her hair blow dried. We then varnished her nails.</p> <p>12.30pm Had lunch with mum & dad then went for a walk to the park. Came home and had a snooze.</p> <p>4.30pm Went for a drive to (nearby town) and visited Ten Pin Bowling Alley. Had some fun with friends and cousins.</p> <p>8.00pm Went to restaurant to have dinner with mum, dad and other family. She loves eating out.</p> <p>10pm Got organised for bed and listened to music in her room.</p>	<p><u>SATURDAY</u></p> <ul style="list-style-type: none"> - up at 10.20 am - following staff around the house during the morning. - to Fund-raising Gala Day at (Provider headquarters) in afternoon (not much fun as it was so wet!). - interactive with staff later on, thoroughly enjoying the company. - short distressed outburst during evening.

<u>SUNDAY</u>		<u>SUNDAY</u>
7.45am	Was wakened to have breakfast & medication then went back to bed to have a lie in.	<ul style="list-style-type: none"> - up at 10.30 am. - changeable mood in the morning - big mood swings. - walk in the park with staff before lunch - became distressed half way through the walk. - laughing when she got home. - changeable mood in evening again, generally relaxing around the house.
10am	Got up and had a shower and had her hair done. Helped to tidy and dust her room.	
2.30pm	Had lunch then lazed around for a while.	
3.00pm	Went for a walk round a shop and had a look round the store. Did not want to spend either her own money or mum's. Had a coffee then walked back home.	
6.30pm	Had dinner with mum and dad then helped to tidy up afterwards. Relaxed and watched some TV.	
8.30pm	Relatives called in for a drink and to bring her a present they had brought her from their holiday. She enjoyed chatting with them and listening to some CDs.	<p>"This is a fairly typical week!"</p>
11pm	Got organised for bed and went up to her room after sharing some sandwiches.	

Appendix 5: Case Studies - Sensitising Concepts

A. Identity and meanings

(N.B. may be embodied - what is this person's expressive medium?)

- Of: personhood ('a human being'), role ('my son', 'a trainee', 'a citizen')
- impairment ('an ordinary bloke' 'a disabled man' 'a severely disabled man')
- home and community
- belonging and participation
- public and private

B. Experiences and expectations

- Of: home, community, services, a day in the life of
- nature and extent of independence, belonging, participation, an 'ordinary life'
- enablers and barriers to these
- (Does an ordinary life require 'extraordinary means'?)

C. Relationships

- Who
- How mediated (communication)
- How perceived (interdependence/dependence)
- How relate to belonging, participation and ordinary life

D. Rights and responsibilities

- Of: pwld, family, those in formal care system, others
- rationale and values - rights, duty, job .
- discharge/experience of in family, community, service systems
- universal and inclusive vs partial and conditional 'thus far and no further', if limits, where, where from, why

E. Reflections on social model

- Review all sections

Appendix 6: Letter to Guardian

(Date)

Dear _____,

Study of the Community Experiences of People with Learning Disabilities and High Support Needs

I enclose some information about this study which I am carrying out in the _____ area.

The name of _____ has been given to me in confidence by _____ as being someone who would be eligible to take part in the study.

I understand that you have responsibility for the affairs of the person concerned and I should be grateful if you would consider whether you would be willing to give your consent for them to take part in this study. Should you give your consent I would not proceed with the research if at any point it appeared to be causing distress to

_____ or if they indicated in some way that they did not wish to continue with the research.

Please return the consent form in the envelope provided. A signed form will be taken as indication that you consent to the research on behalf of

An unsigned form will indicate that you do not give permission for the research.

I should be very happy to discuss the research with you by telephone or in person if you would find that helpful.

Yours sincerely

Lisa Curtice M.A., M.Sc. (Mrs)

Lecturer in Community Care Studies

Appendix 7: Information Sheet

Study of the Community Experiences of People with Learning Disabilities and High Support Needs

The aim of this study is to find out how much people with learning disabilities who have high support needs are able to live an ordinary life like other people and how much they are a part of the community in which they live. How can social inclusion be a reality for people with high support needs? The work has the approval of Council Social Work Department and the NHS Primary Care Trust. This is what the research involves:

The person will be told about the research and their consent requested. If this is not possible people who know the person well and have some responsibility for them will be asked to assess the appropriateness of the research.

The researcher (Lisa Curtice) will make a preliminary visit to find out whether she will need any help to talk to or spend time with the person included in the study and to arrange this.

The researcher would like to spend time with person themselves and also talk to some people who are involved in providing support. The issues observed/discussed will be: where is home for the person, what is their community and what helps and hinders their belonging. The research will involve at least three sessions and not more than six.

Notes will be taken during the interviews and sometimes they may also be tape recorded and written out afterwards. All the information collected for the study will be treated as confidential and kept in a safe place. The real names of individuals will not be used in the research reports or given to anyone else. Any tape recordings made of interviews will be destroyed once the research is completed. The research will be written up as case studies that will highlight issues for ensuring that social inclusion strategies embrace all people, including those with high support needs.

If you would like further information please contact me:

Lisa Curtice

Nuffield Centre for Community Care Studies

University of Glasgow, Gregory Building, Lilybank Gardens

Glasgow G12 8QQ Tel : 0141 330 4194



Appendix 8: Proxy Consent Form

CONSENT TO TAKE PART IN

A Study of Community Experiences of People with Learning Disabilities and High Support Needs

My name is:

I am acting on behalf of:

I have read the information sheet about this study. I understand it and have received my own copy .

I have been offered the opportunity to discuss the study with the researcher and to ask questions about it.

I understand that I am able at any time to withdraw my consent for

..... to take part in the study.

I understand that I do not have to give a reason for this and that any services or support s/he receives will not be affected.

I understand that the information collected for this study will be treated as confidential and that no individuals will be named in the research report or in any publications.

I hereby give my full and free consent for to take part in this study.

Signature:

Date:

Please return in the envelope provided to:

Lisa Curtice
Nuffield Centre for Community Care Studies
Gregory Building, 27 Lilybank Gardens
Glasgow G12 8RZ
Tel 0141 330 4194

Appendix 9: Easy Information Sheet

Information for you to keep!

You are being asked to take part in a study. A study is done to find out information.

This study wants to find out what life is like for people who have support to help them live in the community.

This is what will happen if you are in the study:

- some information about the help you get will be written down.
- someone will come to see you to ask you some questions.
- she would like to come and see you three times. Each time she will stay for about one or two hours.
- if more time is needed to answer the questions she will ask you if she can come back another day. She will not ask to see you more than six times in the course of the whole study. You can always say no to a visit.

She will ask you questions about

- the people you know
- the things you like to do
- the places you know well.

She will also ask if she can spend some time with you in a place you know well.

She will also speak to someone who spends a lot of time with you about the things you like to do. You can know who she is speaking to.

They may help you keep a book to show all the things you do in a week.

You do not have to do this. You can say NO at any time. You do not have to give a reason.

You do not have to answer any questions you do not like.

Any services or help you get at the moment will not change because you do or do not take part in this study.

The information will be written down but it is private and will be kept safe. It will be used to write a story about your life and the lives of some other people. Others will read these stories but they will not be able to recognise you personally from reading them. We will not tell them things you do not want them to know.

Any tape recordings we make to remind us of what you have said will not be kept once the research is completed.

If you have a question about this you can contact me. You can also ask someone to contact me for you.

I am: Lisa Curtice

My telephone number during the day is: 330 4194

My address is:

Nuffield Centre for Community Care Studies

The Gregory Building, University of Glasgow,

Lilybank Gardens, Glasgow G12 8QQ

Appendix 10: Consent Form

..... Primary Care Trust

..... Council Social Work Department

CONSENT TO TAKE PART IN

A Study of People's Experiences in the Community

My name is:

I have read the information/been told about this study.

I understand it and have my own copy of the information.

I have been able to talk to the researcher and to ask her questions about it.

I understand that I am able at any time to say no to taking part in the study.

I understand that I do not have to give a reason for this and that any services or support I receive will not be affected.

I understand that the information collected for this study will be kept safe and private and that my name will not be used in any writing about it.

I agree to take part in this study.

Signature

Date

I confirm that this person has been given information about this study and that they have freely given their consent.

Witnessed by (name)

Signature

Date

Lisa Curtice Tel 0141 330 4194

Nuffield Centre for Community Care Studies

The Gregory Building, University of Glasgow, Lilybank Gardens

Glasgow G12 8QQ

Appendix 11: Topic Guide - Person with Learning Disabilities

First session

Explain more about research and check consent if possible

Introduce self and get to know person a bit and what they like to do

Explore 'where and what is home'

(time about one hour)

Second session

Remind of previous visit (photograph?) and check consent if possible

Administer Part 1 of ABS Scale (approx. 45 mins)

Explore 'the people who are important to me' drawing on diary information

Explore 'what I like to do'

(time about one hour and a half)

Third session

Re-introduce self and research, remind of previous visits and check consent if possible

Check any incomplete items on ABS

Spend time (by prior arrangement) with the participant in a place important to them

Explore feelings about 'my community'

Appendix 12: Topic Guide - Supporter

Initial visit

- Introduce research and check consent
- Discuss study requirements
- Discuss communication needs of person with learning disabilities

Following first session with person with learning disabilities

- Show the diary sheets and how to complete
- Find out if other diarists needed
- Arrange trial day if wanted
- Agree dates of 'diary week' and how to return sheets
- Stress need for confidentiality of diary information

First interview (following diary week and second session with person with learning disabilities)

- Use diary information to review and discuss social network diagrams
- Explore a typical day - activities, people and places important to the person with learning disabilities
- Arrangements for visit with person with learning disabilities

Second interview (following visit with person with learning disabilities)

- Explore critical incidents of a) the person being included and b) the person being excluded from their 'community'

Appendix 13: Letter to Policy Informants

Citizens: a study of social inclusion and people with learning disabilities and high support needs living in the community

I am seeking to speak to a group of experts such as yourself, within the social and health services, in connection with the above study of social inclusion and people with high support needs. The aim of this research is to investigate the extent to which people with learning disabilities who also have high support needs experience inclusion and full citizenship. It will consider the issues that arise in extending ordinary life principles within services and communities. I wish to interview a service commissioner with responsibility for services for people with learning disabilities in each Scottish local authority and health board. The purpose of the interview is to obtain strategic views on policies and service responses to people with high support needs.

I understand this to be your speciality and it would therefore be extremely useful if I could speak to you about these issues. Interviews will be by telephone and will last a maximum of 40 minutes. The interviews will be conducted during September and October 1999. With your permission I should like to tape record the interview.

This study has been approved by the Research and Training Standard Committee of ADSW. The Scottish Office Review Team are also aware of the study and will be informed of any recommendations that emerge. No information will be reported in a way that identifies authorities, boards or individual respondents.

I will telephone shortly to arrange a date and time for a telephone interview. I am hoping to complete the interviews this millennium! Your contribution would be greatly valued.

Yours sincerely

Lisa Curtice (Mrs)
Lecturer in Community Care Studies

Appendix 14: Topic Guide Policy interviews

Priorities

What do you see as the most important needs that learning disability services have to address in your area?

Request documents:

learning disability strategy

planning assumptions: needs & numbers

service configurations

What are the particular issues currently for people with high support needs?

probe: definition

What are biggest hurdles that you envisage in the next 12 months in developing services for people with high support needs?

Philosophy

Could you say something about the philosophy or approach that you feel that you are working with in developing services for pwlds?

probe:

specialist/ordinary life

integration/inclusion

individual/community

market/other

May I ask you whether you think that life in the community is a possibility for anyone or are there certain reasons why life in the community would not be feasible?

probe: risk to person; risk to community; cost; other

Services

Could you tell me about the range of care packages that are currently provided to pwlds in the community? (costs if poss)

could you describe an intensive package?

could you describe a low intensity package?

What proportion of services for pwlds are provided in house?

Is commissioning in place for all services for pwlds or only for certain services or groups?

In your approach to developing services/opportunities for people with high support needs what sort of balance between specialist and generic provision do you favour?

Partnerships

To what extent is there effective collaboration between agencies in your area to meet the needs of pwlds, for example with respect to health needs?

Explore possibility of filling in network diagram by post showing relationships, strength and where there are contractual links

Who or what is driving partnerships in this area, would you say?

National policy

The Scottish Office, as you might know, is just beginning to put together a national strategy for learning disabilities,

What kinds of support from the centre would make a difference to your capacity to improve support for pwld?

Close

I'm very grateful for the time you have given to this discussion, which I've really enjoyed. I feel I now have a much clearer picture of the issues in

Before we wind up, is there anything you would like to add that you feel might be helpful or that you have just not had a chance to say?

Thanks

Promise to send summary of interview for amendment
Check out where to send follow up request for stats and docs
Promise summary of results.

Appendix 15: List of Local Authority Policy Interviews

Local Authority	Date of interview
Aberdeen City	20.12.99
Aberdeenshire	05.12.99
Angus	01.12.99
Argyll & Bute	10.12.99
City of Edinburgh	02.02.00
Clackmannanshire	28.10.99
Dumfries & Galloway	07.06.00
Dundee City	-
East Ayrshire	18.12.99
East Dunbartonshire	09.11.99
East Lothian	16.12.99
East Renfrewshire	16.12.99
Eilean Siar	16.12.99
Falkirk	21.12.99
Fife	21.06.00
Glasgow City	29.09.99
Highland	13.10.99
Inverclyde	-
Midlothian	20.12.99
Moray	21.12.99
North Ayrshire	-
North Lanarkshire	14.06.00
Orkney Islands	02.12.99
Perth & Kinross	15.12.99
Renfrewshire	07.06.00
Scottish Borders	03.12.99
Shetland Islands	07.06.00

South Ayrshire	21.10.99
South Lanarkshire	05.10.99
Stirling	09.06.00
West Dunbartonshire	22.03.00
West Lothian	-
Health Board	
Lanarkshire	23.06.00

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